

# Summary, including the ACA checklist

## Summary

General practitioners (GPs) play a central role in providing palliative care in many countries. In order to provide high-quality care, effective communication between health care professionals and patients is considered to be an essential requirement. GP-patient communication in palliative care will often be difficult, due to the severity and complexity of this situation, involving a mix of medical, psychological, social and spiritual/existential issues. If the communication is not effective, some, if not many, of the problems that patients are facing might not be identified by GPs. Consequently, it is likely that GPs will not be able to take the appropriate actions, and the patient's quality of life may be unnecessarily impaired. Knowledge about factors that hinder or facilitate GPs in their communication with patients in palliative care is needed for the development of effective training programmes to equip GPs to be effective communicators, and ultimately to improve the quality of the palliative care they provide and the quality of life of their patients.

The aim of the research project described in this thesis was to develop and test a communication training programme for GPs and GP trainees providing care to patients in palliative care, in order to improve health-related patient outcomes. The project comprised three parts: (1) explorative studies; (2) development of a communication training programme; and (3) experimental studies.

### (1) The explorative studies

In **chapter 2** we reported on a systematic **review** of the literature aimed at identifying facilitators of and barriers to GP-patient communication in palliative care based on a search in seven computerized databases. The most frequently reported facilitators were: the availability of the GP, longstanding GP-patient relationships, GPs showing commitment, being open and allowing any topic to be discussed, being honest and friendly, listening actively and taking patients seriously, taking the initiative to talk about end-of-life issues, not withholding information, negotiating palliative care options, being willing to talk about the diagnosis and prognosis, preparation for death, the patient's psychological, social and spiritual issues and the patient's end-of-life preferences. The most frequently reported barriers were: the GP's lack of time, the patient's ambivalence or unwillingness to be informed about the prognosis, and the GP not talking honestly about the diagnosis or prognosis. The results of our review suggest that, to be effective communicators in the palliative care setting, GPs should be available for their patients, and take the initiative to talk honestly about the many relevant end-of-life issues.

In **chapter 3** we presented the results of a **qualitative study** on facilitators of and barriers to GP-patient communication in palliative care. For this study, we interviewed palliative care patients, asked GPs to discuss this issue in focus groups, and asked end-

of-life consultants to complete a questionnaire. Patients as well as GPs valued accessibility, taking time, showing commitment, and listening carefully as facilitators. Barriers reported by GPs as well as end-of-life consultants were difficulty in dealing with a former doctor's delay and with strong demands from a patient's relatives. Almost all participating end-of-life consultants had observed problems in GP-patient communication in the past year (e.g., GP failing to clarify the patient's concerns sufficiently, GP not anticipating various scenarios). The results of the qualitative study suggested that the quality of the GP-patient communication in palliative care could be improved. More specifically, to communicate effectively GPs should pay attention to how they communicate with their palliative care patients (for example, taking time, listening carefully, being willing to talk about any subject, reflecting on their own personal barriers), and they should take the initiative more often to discuss several end-of-life issues (e.g., the unfavourable prognosis, unfinished business, end-of-life preferences).

## **(2) The development of the ACA communication training programme**

In **chapter 4** we described the **development** of a new palliative care specific communication training programme for GPs and evaluated the **first experiences** of a group of GPs and a group of GP trainees with this new training programme. To support this new training programme we developed the 19-items checklist which summarized the GP-related facilitators identified in the explorative studies, divided into three categories: [1] the *availability* of the GP for the patient, [2] *current issues* that should be raised by the GP, and [3] the GP *anticipating* various scenarios (ACA). To assess the applicability of the programme we evaluated the rate of attendance of GPs and GP trainees and their appreciation of the different steps of the programme. The ACA checklist was appreciated by GPs as useful both in practice and as a learning tool, whereas GP trainees mainly appreciated the list for use in practice.

## **(3) The experimental studies**

In **chapter 5** we reported on a controlled **trial** that evaluated the effectiveness of the ACA training programme on outcomes at the GP level. To determine these outcomes, we performed a quantitative content analysis (Roter Interaction Analysis System = RIAS) of one videotaped consultation of each GP with a simulated palliative care patient conducted at baseline, and one at twelve months follow-up. Both how the GP communicated with the patient ('availability') and the number of current and anticipated issues the GP discussed with the patient were measured. We found no effect of the ACA communication training programme on the total number of current and anticipated issues that GPs discussed in the simulated consultations, or on the quality of their communicative behaviour.

In **chapter 6** we presented the same controlled **trial** to evaluate effectiveness of the

ACA training programme but reporting outcomes at patient level. We asked real palliative care patients of the participating GPs to complete a questionnaire at baseline and at 12 months follow-up. Outcomes were: palliative care outcomes (the Palliative Care Outcome Scale [POS], the EORTC Quality of Life Questionnaire Core 15 Palliative [QLQ-C15-PAL] and the Rest & Peace Scale); satisfaction with the communication with their GP (the Patient Satisfaction Questionnaire-III [PSQ-III]); and the patient's perception of the GP's availability and the extent to which current and anticipated issues were discussed (the ACA scale). We also found no effect of the ACA training programme on these patient reported outcomes.

In **chapter 7** we reported on a similar controlled trial to evaluate the effectiveness of the ACA training programme but among third years GP trainees. For each GP trainee, we videotaped a consultation with a simulated palliative care patient at baseline and at six months follow-up. Outcomes were the same as used in chapter 5. We found no effect of the ACA communication training programme on the total number of current and anticipated issues that GP trainees discussed in the simulated consultations, or on the quality of their communicative behaviour.

The descriptive results from both controlled trials suggest that, although palliative care patients were generally quite satisfied with the communication and palliative care provided by their GPs (chapter 6), GPs and GP trainees should take the initiative more often to discuss certain end-of-life issues, including spiritual/existential issues, unfinished business, prognosis and possible complications, the actual process of dying, and end-of-life decisions (chapter 5-7).

Finally, in **chapter 8** we summarized the main findings of our studies and discussed methodological considerations and the implications of our results for general practice, GP vocational training, and future research.

While many studies on effectiveness of communication skills training among oncologists and oncology nurses found positive effects on health care professional level and only few effects on patient-reported outcomes, we found no effects of the ACA training programme at GP (trainee) and patient level. Including GPs who already had chosen to participate in a two-year Palliative Care Peer Group Training Course and third years GP trainees may explain, at least in part, the high level at baseline of most of our outcomes at GP (trainee) and patient level, which allowed little room for improvement on these outcomes over time (ceiling effect). Besides, in spite of the high total number of issues discussed in a consultation, there seems to be room for improvement on the scores in some current and anticipated issues. The effectiveness of the programme might be increased by including a broader sample of GPs and by focusing on the issues which were discussed less often in our studies.

## The ACA checklist

### *Availability (of the GP for the patient)*

- (1) Taking time
- (2) Allowing any subject to be discussed
- (3) Active listening
- (4) Facilitating behaviour (e.g. empathic, respectful, attentive, occasionally also phoning or visiting the patient spontaneously)
- (5) Shared decision-making with regard to diagnosis and treatment plan
- (6) Accessibility (e.g. phone numbers)

### *Current issues (that should be raised by the GP)*

- (1) Diagnosis
- (2) Prognosis
- (3) Patient's physical complaints and worries
- (4) Patient's psychosocial complaints and worries
- (5) Patient's spiritual/existential complaints and worries
- (6) Wishes for the present and the coming days
- (7) Unfinished business, bringing life to a close
- (8) Discussing treatment and care options (concerning current issues 1-7)

### *Anticipating (various scenarios)*

- (1) Offering follow-up appointments
- (2) Possible complications
- (3) Wishes for the coming weeks/months (personal wishes as well as preferences with regard to medical decisions)
- (4) The actual process of dying (final hours/days)
- (5) End-of-life decisions