Development of a patient assessment to meet the needs of patients suffering from advanced non-oncological diseases – the KOPAL study

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Abstract

Background

To develop an aide memoire for patients diagnosed with advanced non-oncological chronic diseases, the KOPAL conversation guide, to foster interprofessional counselling between GPs and specialist palliative home care teams.

Methods

As part of the multi-centre, two-arm, cluster randomised controlled KOPAL study, the draft of the conversation guide was discussed and consented in three focus groups with 4 patients, 7 health care providers, and 5 stakeholders.

Results

The final version of the KOPAL conversation guide contains eight key topics: living with the illness, physical situation, emotional situation, personal situation, social situation, information and communication, control and autonomy, emergency management. Each topic refers to different general points, which are listed on top of the respective thematic section. The conversation should start by addressing the patient's today's well-being and end by asking for the patient's main topic based on the discussed issues.

Conclusions

The KOPAL conversation guide is a broad evaluation and communication tool that covers potential palliative care (PC) needs of non-oncological patients and provides a basis for interprofessional case planning and counselling. Applying the KOPAL conversation guide may help to bridge the communicative gap between general and specialist PC professionals and between professionals and patients.

Background

Demographic change leads to a growing number of older persons with serious chronic conditions and will be a major challenge for health care in general and for end-of-life care in particular. [1] [2] Non-oncological chronic conditions are characterized by long duration, slow progression, and prognostic uncertainty. [3] Patients suffering from progressive non-oncologic chronic diseases are mainly treated in primary care. [4] In Germany, outpatient palliative care (PC) is structurally separated in two areas: general PC provided by general practitioners (GP) and specialist palliative care (SPC) provided by trained doctors, nurses and other professionals.

Meanwhile it has often been discussed that early integration of PC can, amongst others, improve patients' quality of life, reduce burdensome physical symptoms, increase advance directives, and improve caregiver burden as well as patient and family satisfaction. [5] In their review Davis et al. [5] show that there is no common definition of 'early' palliative care, but "it does appear that for full benefits of palliative care to be realized, continuity by a multidisciplinary team is needed for at least 3–4 months." However, a retrospective cohort study including 4650 patients conducted from 2012 to 2014 in the UK showed a median duration of 34 days (MAD = 29 days), whereas half of the study population had a duration that deviated up to 29 days. Cancer patients received a longer median duration of PC than patients with other conditions (MAD = 31 days vs. MAD = 14 days). [6] A systematic review from 2020 including 169 studies shows that PC is provided less than 19 days before death, with a large diversity across the countries and a longer duration for cancer patients compared to those without oncological diseases. [7] This suggests that improvement of PC provision is still needed, especially for non-oncological patients. [8] Research indicates that most common chronic conditions in primary care in Germany relate to the cardiovascular system (e.g., congestive heart failure (CHF), coronary heart disease, hypertension), the nervous system (mainly dementia) and the respiratory system (mainly chronic obstructive lung disease), which are also among the most important chronic diseases worldwide. [3,9]

Patients suffering from progressive non-oncological chronic diseases often experience only minor limitations in everyday life over a long period of time which are followed by serious episodes of illness or crises. [1,10] These illnesses typically follow two trajectories of functional decline described by Lynn and Adamson [1], empirically validated by Lunney et al. [11]: 1) Long-term limitations with intermittent exacerbations and sudden dying (typical for organ and system failure) and 2) prolonged dwindling (typical for dementia, disabling stroke, and frailty). This makes it more difficult for GPs to identify the appropriate time to provide either generalist PC themselves or to initiate SPC providers. However, especially those patients diagnosed with chronic cardiorespiratory diseases experience distressing symptoms similar to cancer patients at an advanced stage of disease. [12] Many screening tools to identify patients with potential PC needs have been developed in the past. However, most of these tools "use prediction of death and/or deterioration as a proxy for the identification" of patients who are likely to have unmet PC needs. [13]

On this background, using only a single screening tool might not be sufficient. A timely interprofessional and interdisciplinary counselling between GPs and multidisciplinary specialist palliative home care teams (SPHC) using an aide memoire for non-oncological patients, e.g., the "KOPAL conversation guide" could complement the counselling.

Methods

Study Aim and Design

The KOPAL conversation guide aims to cover relevant care aspects and to reveal individual gaps and needs in healthcare provision. The KOPAL conversation guide has been developed as part of the KOPAL-

study [14] and will be presented in this paper. The process of development was guided by the following question: Which key topics and detailed foci should be addressed to fully identify possible palliative care needs of patients suffering from progressed non-oncological chronic diseases?

The KOPAL-study is a multi-centre, two-arm, cluster randomised controlled trial (RCT). The design of the study has been described elsewhere. [14] In brief, the study is conducted in three steps: 1) Development of the KOPAL conversation guide, 2) intervention (home visit by SPHC nurse followed by a brief SPHC team consultation and an interprofessional telephone case conference between GP, SPHC nurse and SPHC doctor to discuss the patient's health and care situation and needs) and quantitative investigation at baseline and four follow-up points within 48 weeks, 3a) health economic analyses and 3b) qualitative evaluation of the KOPAL-intervention. In this paper, we describe step 1, development of the KOPAL conversation guide. The is used in step 2 as conversation tool for the SPHC nurse home visit and, if desired, for the telephone conference. SPHC nurses will receive a full online training on the use of the guide. In step 3b, the intervention, including the application of the guide, will be evaluated and, if needed, modified afterwards.

Development of the KOPAL conversation guide

Preparation

The KOPAL conversation guide is based on the British 'PEPSI COLA aide memoire' (used with permission from the National GSF Centre in End of Life Care) a holistic patient assessment covering 9 core topics: Physical, Emotional, Personal, Social Support, Information/Communication, Control and Autonomy, Out of Hours, Living with illness and After Care. The aide memoire includes numerous topics for consideration, related cue questions, and resources. [15]

As a first step, we drafted a German version of the PEPSI COLA aide memoire eliminating cancer related issues since the KOPAL conversation guide focuses on non-cancer patients. After conducting a narrative review the draft has been revised and discussed several times within the multidisciplinary team including doctors, nurses, sociologists, psychologists, health scientists, and nursing scientists. Aim of the narrative review was to identify key topics in the field of end-of-life care with relevance for patients diagnosed with advanced non-oncological chronic-disease.

Workshops

The KOPAL conversation guide has been subsequently discussed in three expert workshops (WS) with patients diagnosed with COPD or CHF (WS 1), health care providers of the field of primary and palliative care, cardiology and pneumology (WS 2), and stakeholders (i.e. researchers, health care providers, patients representatives, WS 3). Since the guide was built on the well accepted PEPSI COLA aide memoire, a special focus was on the issues that explicitly point out potential unmet needs with regard to non-oncological long term illness with slow progress. The KOPAL conversation guide has been revised after every WS. The revised version provided the basis of discussion for the next WS (see Fig. 1).

Participants

WS 1. Participants were recruited in an outpatient clinic for primary care via information material or direct invitation by physicians. Participants were included if they had a documented diagnosis of an advanced COPD or CHF or if they were relatives of people suffering from advanced dementia. WS 2. GPs, cardiologists, and pulmonologists were recruited via previous institutional and personal professional contacts. Local outpatient PC providers were contacted via written invitation. WS 3. Stakeholders were recruited regarding different professions and disciplines by contacting different clinics, practices, research institutions and patients' organizations. Researchers and participants of WS 1 and 2 met for the first time during the WS. Some participants of the third WS were known through previous professional contacts. Participants of the third WS were also members of the advisory board of the KOPAL study.

Participants did not get any incentives. Since personal data of patients was not targeted, written informed consent was not required. In case personal illness experiences were narrated, patients signed a privacy policy in advance. Demographic data of participants were not collected. The Ethics Committee of the Medical Association Hamburg, Germany (no. PV7090) approved the study.

Discussions

The topics of the KOPAL conversation guide were discussed during three two-hour focus groups (FG) considering the different perspectives (patients/relatives, providers, stakeholders). FG were moderated by two experienced researchers (NP, GM both PhD) and observed by a third researcher (TM, M.A.). At the beginning of each WS participants were introduced to details of the study in general and the KOPAL conversation guide in particular. Each participant received a preliminary version and could refer to details at any time. During the first part three predefined questions lead the discussion of each WS: '*Which issues do you want to talk about?*', '*Which issues do you not want to talk about in any way?*', and '*What is good / bad? - Please explain*'. Participants were asked to imagine themselves in the situation of using the KOPAL conversation guide. In a second step, the KOPAL conversation guide was reviewed with a focus on the following questions: '*Which topic is relevant?*', '*Which topic is dispensable?*', '*Which topics / issues should be added?*'. All statements were documented immediately, visualised for all participants and discussed until consent was reached. Discussions were not audiotaped.

After each WS, the KOPAL conversation guide was revised and the revised version was discussed in the following WS. In case of conflicting statements between focus groups the respective issues were discussed and consented within the research team afterwards.

Results

In total, 4 patients, 7 health care providers, and 5 stakeholders participated in the workshops (WS 1: n = 4 patients; WS 2: n = 4 healthcare providers; WS 3: n = 8 stakeholders). Relatives of patients with dementia could not be recruited. Their perspectives were taken into account by participation of a respective patient

representative in the third workshop. All workshops were conducted at the department of the consortium leader.

Key topics of the KOPAL conversation guide

The first version of the KOPAL conversation guide covered nine key topics: living with the illness, physical situation, emotional situation, spirituality, sexuality, social situation, information and communication, control and autonomy, emergency management. The topics should cover at least three main issues: (1) Four dimension of the human, (2) patients' needs, and (3) health related quality of life. (1) The *four dimensions of the human* are central in the holistic approach of palliative care as stated in the S3-guideline Palliative Medicine for cancer patients [16]: *physical dimension* (somatic issues), *psychological dimension* (cognitive and emotional dimension), *social dimension* (relational dimension of human relationships with special focus on relatives), *spiritual dimension* (including experiencing or seeking for individual and covering existential questions, e.g., identity, obligation, hope, love, values (relationship to the family, friends, nature, culture, life itself) and religious aspects (belief, religious practices, relationship to God or transcendent). (2) The S3 guideline for palliative care distinguishes between individual need (a subjective-individual wish or an experienced state of stress of a person combined with the wish for relief) and objective need (an objectively recognisable, comprehensible state of stress of a patient that cannot be remedied by his or her own resources). Resources are defined as material or individual/social capabilities to solve the burdensome situation. [16] (3) The health-related quality of life is a key factor in PC refers to the patients' self-assessment regarding physical, psychological, social and daily aspects of wellbeing und functionality.

The KOPAL conversation guide should be used as an aide memoire in order to cover all potentially relevant issues and should be used in an open manner. However, additionally, some validated standardised scales are provided which are commonly used in palliative care: The German Version of the Distress Thermometer of the National Comprehensive Cancer Network (NCCN Distress Thermometer) [17,18], the Minimal Documentation System for palliative medicine (MIDOS) [19] and the genogram, provided by the German Association of Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin, DGP) to capture the patients social environment [20] were included with permission of the authors.

Workshops

After discussion in the WS the participants suggested to revise six main aspects of the KOPAL conversation guide. 1) The first version of the guide provided space to document instructions at the end of each key topic. Participants found that this could lead to an increased structure of the conversation between PC nurse and patient. Instead, the conversation should be conducted according to the patient's preferences and relevancy. PC nurses should be able to document the content of the conversation, relevant agreements and possible recommendations to be presented in the case conference. 2) The patient's current health care provision with special focus on nursing should be documented in more detail, e.g., does an adequate care level (Pflegegrad) exist, how often does the patient receive nurse home visits, how many physicians are involved? 3) Sexuality was discussed as relevant topic within PC but should be

addressed carefully. Since patients as well as nurses showed reservations, the key topic 'sexuality' was renamed to 'personal situation' comprising cultural, sexual and spiritual needs. 4) Participants found that patient's knowledge regarding the course of the disease and their understanding of an emergency situation should be addressed (including emergency management). Further it should be documented whether the patient needs more information. 5) Regarding the key topic 'control and autonomy' patients should not only be asked in case of decreased health about where they want to be cared for, but also how. 6) Finally, patients should be asked about their knowledge regarding emergency management, e.g., if they can distinguish between a crisis and an emergency situation and how they could regulate themselves within a crisis (e.g., by using breathing techniques).

Furthermore, participants of the WS suggested to start the conversation by addressing the today's well-being and to end it by asking the patient to name his/her own main topic based on the discussed issues. The goal should be to address all key topics but adapt the course of the consultation to the individual situation in order to conduct a personal and patient-orientated talk. Table 1 shows the key topics of the KOPAL conversation guide.

Table 1
Topics of the KOPAL conversation guide

Introductory question	*'How are you feeling today?'*
Key topics	General points to be addressed
Living with the illness	Current care needs of the patient such as: rehabilitation support, admission to other health facilities, non-medical support (e.g. physiotherapy, social services, nutrition counselling), need for medical aids)
Physical situation	Current physical complaints and needs such as: symptoms, medication (regular or on-demand medication), review of current non-essential treatment, side-effects
Emotional situation	Current emotional complaints and needs such as: restlessness, anxiety, joy, loneliness, coping-strategies
Personal situation	Current cultural, sexual and emotional needs such as: cultural: migration background, sexual: physical closeness, relationship problems, homosexuality, gender identity, spiritual: religion, spiritual needs, pastoral care, meaningful life
Social situation	Current social relations, social activities, social support such as: daily activities, social integration, social activities (e.g. parlour games, walks), social support (e.g. Caritas, Red Cross), coping with daily activities, communication
Information and communication	Current information level und communication needs such as: illness knowledge, course of the illness, emergency needs, shared decision making, practical assistance (e.g. logopaedic, ophthalmology, audiology, translation service, self-help group)
Control and autonomy	Current needs on control and autonomy (advance care planning) such as: living will, power of attorney, treatment plan, care plan near to death, preferred place of care (e.g. care support, hospice service), burial (in Germany with reference to § 132g SGB V Gesundheitliche Versorgungsplanung für die letzte Lebensphase)
Emergency management	Arrangements of emergency situations such as: emergency medical form (Ärztlicher Notfallbogen, ÄNo), "do not resuscitate", emergency service of the Association of Statutory Health Insurance Physicians (KV-Notdienst), emergency home care, list of national and personal emergency numbers / contact numbers
Final question	*'We talked about different issues. What is your main topic or main concern?'*

Discussion

The final version of the KOPAL conversation guide contains eight key topics: living with the illness, physical situation, emotional situation, personal situation, social situation, information and communication, control and autonomy, emergency management. Each topic refers to different general points which are listed on top of the respective thematic section. Providers can use these points as memory aid and document their assessments in free text. In addition, some specific issues of high relevance are pre-formulated as open or closed questions; answers can be documented via check-box or free text.

Identification of the start of a palliative trajectory is difficult, especially regarding non-oncological diseases such as COPD, CHF and dementia. [21] Valid scales to define the starting point for PC do not exist and various tools to predict the illness trajectory are inaccurate. [21–23] The surprise question (*Would I be surprised if this patient died within 12 months?*) was known as a tool of variable accuracy and could be a simple tool to screen patients for PC needs. However, in their recent study comprising six European countries, White et al. [24] showed that there is a high level of inconsistency amongst GPs and therefore the Surprise Question does not seem capable for prognosis. The Double Surprise Question (original Surprise Question plus *Would I be surprised if this patient is still alive after 12 months?*) was shown to be more accurate to identify palliative care needs of patients with cancer [25], but it has to be taken into account that at a certain stage of the disease the illness trajectory of patients with cancer is, in comparison with those diagnosed with non-oncological disease, easier to predict. However, patients with non-oncological disease might have health care needs on different levels and comprising different topics or dimension over a period of more than one year. It might be arguable whether an assessment should identify the switch from curation to palliation since the provision of primary and (specialist) palliative care should not be a decision between either the one or the other. [26] Maddocks et al. [26] suggest partial integrative palliative care when indicated within the individual illness trajectory, as for example in connection with exacerbation or other decline. The KOPAL conversation guide facilitates to identify the resulting potential needs of patients and/or relatives/informal caregivers and to initiate appropriate measures.

A major problem regarding PC provision is physicians' reluctance to consider and to discuss PC options. Underlying reasons are experienced patient's reservations or the fact that non-oncological diseases are not directly connected with dying. [22,23] Furthermore, improvement is needed regarding GPs team approach, such as communication with other health care providers. [27]

Regarding these difficulties and reservations, the KOPAL conversation guide focusses particularly on potential needs that might be overseen within the slow illness progress. [28] These are, amongst others, long-term care grade, home medical equipment, social integration (stigmatisation and isolation over a long period), advance care planning, and emergency management. Hickman et al. described reasons for discordance between advance care planning documentation (Ärztlicher Notfallbogen, ÄNo) and patient preferences. [29] The KOPAL conversation guide may help to identify patients' preferences and foster concordance.

The strength of this study is that the perspectives of relevant actors (patients, health care providers and experts) had taken an active part in the development of the KOPAL conversation guide. A weakness is, that only few patients and health care providers agreed to take part in the workshops 1 and 2. The conversations, on the other hand, were trustful and issues had been intensively discussed because of the homogeneous group composition (patients only and health care providers only). Furthermore, the perspectives of relatives and informal caregivers, especially those of patients with dementia, could not be taken into account, since they could not be recruited. However, this perspective will be part of the

qualitative evaluation of the KOPAL study. Also, the perspective of dementia was covered by a patient representative in WS 3.

Conclusions

With the KOPAL conversation guide we developed a broad evaluation and communication tool for the assessment of PC needs of non-oncological patients. The guide can be applied by SPHC nurses followed by an interprofessional case conference to strengthen nursing aspects in general palliative care. Therefore, it provides a basis for interprofessional care planning and counselling. One could also imagine, that other health care providers apply the guide and act as an interface between GPs and patients on the one hand and between GPs an SPHC on the other hand. Thus, the KOPAL conversation guide implies the chance to foster timely general or specialist PC including various relevant aspects that meet the goal of PC in general: improving health related quality of life, reducing symptom burden, and enhancing patient and caregiver satisfaction. Furthermore, applying the KOPAL conversation Guide in practice may help to bridge the communicative gap between all general and specialist PC professionals and between professionals and patients. However, GPs should be attentive regarding the stage of the disease. Increased hospitalisation, for example, could be an indicator for the need of interprofessional case conferences to evaluate potential PC care needs.

Declarations

Ethics approval and consent to participate

The Ethics Committee of the Medical Association Hamburg, Germany (no. PV7090) approved the KOPAL study. *The need for informed consent for taking part in the workshops in step 1 (preparation) was waived by this Ethics Committee due to the fact that no patient related data was generated in this step. All methods used in the KOPAL study were carried out in accordance with the Declaration of Helsinki.* All authors confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Consent for publication

Not applicable

Availability of data and materials

All data generated or analysed during this study are included in this published article. The KOPAL conversation guide is available on request from the corresponding author (GM).
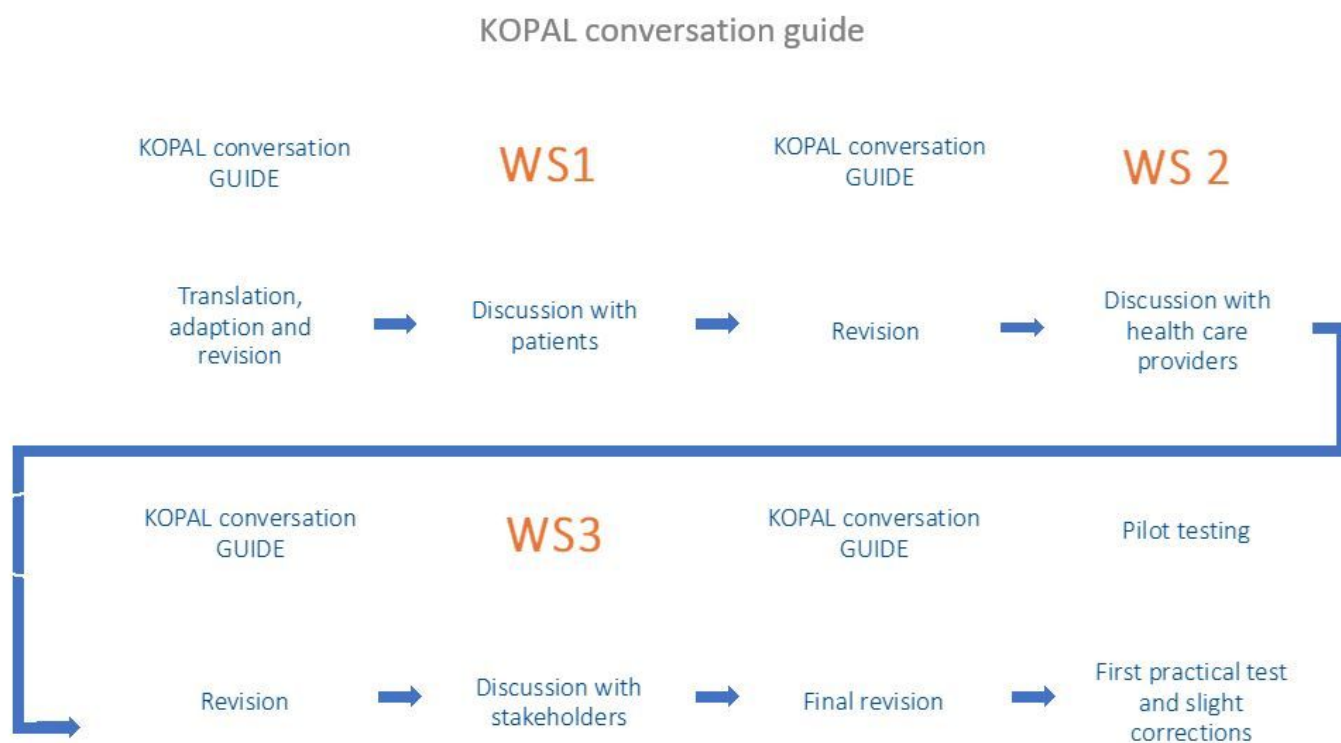
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Figures

Figure 1

Work flow