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Key elements for the education and counselling of patients treated with oral anticancer drugs

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ABSTRACT

Purpose: The process of education and counselling of patients treated with oral anticancer drugs, aimed to achieve adequate self-management, involves different stakeholders (i.e. physicians, oncology nurses, pharmacists) from primary and secondary care. However, currently no guiding principles exist on how to organize and perform education and counselling for these patients. Therefore, the purpose of this study was to develop and build consensus on key elements for the education and counselling in patients on oral anticancer drugs.

Methods: A multi-method approach combining a literature search, semi-structured interviews with patients and healthcare professionals, and input from experts were used to develop an initial list of key elements. Subsequently, consensus was built in a two-round Delphi-study, involving patients and healthcare professionals from primary and secondary care. Key elements were retained if at least 80% of respondents in all groups considered the element as important or if in at least one group 90% consensus was reached.

Results: The initial list contained 110 key elements, divided in 7 themes: coordination of care, patient contacts: style and content, medication counselling at the start of the treatment and during follow-up, psychosocial support, and involvement of family and friends. After the first Delphi round, 80% consensus was reached for 23 elements; 6 new key elements were added. After the second round, 80% consensus was reached for 51 out of 116 elements; 31 elements were added following the 90%-rule, yielding a list of 82 elements.

Conclusion: The final list of 82 key elements, obtained in this study, could be used to develop clinical pathways that guide adequate education and counselling of patients on oral anticancer drugs. Due to the open description, the implementation of these elements can be adapted to the specific context and composition of the oncology team.

1. Introduction

Over the last decades, an exponential increase in the development and use of oral anticancer drugs (OACD) has been observed (O'Neill and Twelves, 2002; Weingart et al., 2008). Traditional intravenous therapies are administered in a relatively controlled environment by experienced healthcare professionals (HCPs). Since oral therapies can be provided at home, patients now play a substantial role in their own treatment (Bassan et al., 2014; Kav et al., 2008).

Many advantages are linked to the use of OACD. First, it improves quality of life (QOL) by its convenience and ease of use and by reducing hospital stay (Borner et al., 2001; Timmers et al., 2014). Second, there is no need to enter veins, which gives a feeling of freedom and a strong sense of control over one's treatment and over the evolution of the disease (Liu et al., 1997). It is therefore not surprising that patients prefer the oral administration to intravenous therapy (Fallowfield et al.,

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2006; Liu et al., 1997; Twelves et al., 2006). As the role and responsibility of these patients in their treatment increases, adequate patient education and counselling on these drugs is primordial. Patient education can be defined as "any set of planned educational activities designed to improve patients' health behaviours and/or health status" (Lorig, 1991). Patient counseling refers to "an approach that focuses on enhancing individual problem-solving skills for the purpose of improving or maintaining quality of health and quality of life" (Yeung et al., 2012). During medication-counseling, HCPs should therefore discuss medication information, with respect to the physical, psychological, sociocultural, emotional and intellectual perspectives, health beliefs and values of the patient (Cavaco, 2019). In chronic conditions, patient education and counseling are key aspects in the guidelines for disease management and aim to ensure effective patient self-management (Legido-Quigley et al., 2013). As OACD are often taken on a long-term basis, the importance of disease, symptom and medication management is comparable to the importance in other chronic conditions. However, today, no recommendations on key elements (KE), necessary to educate and counsel patients treated with OACD, are available (e.g. items to be discussed at the start of the treatment and during follow-up, how to involve family and friends, …).

The use of OACD poses important challenges on the level of the patient. Patients following an oral anticancer treatment should be able to self-manage their condition. This means that they should know how to take their medicines as prescribed by their physician, how to handle these drugs safely, how to manage possible side effects and when to contact a specialized HCP in case of serious toxicities and other problems or questions (Findlay et al., 2008; Weingart et al., 2008). Furthermore, due to the chronic character of the treatment and the fact that these drugs are self-administered, issues related to adherence should not be neglected (Moore, 2007). In the past decade, various studies have been performed in patients with an oral anticancer treatment studying the extent of non-adherence and its contributing factors (Bassan et al., 2014; Verbrugghe et al., 2016). The systematic review of Greer et al. (2016) reports adherence rates between 46%–100% depending on the studied sample, the calculation-method for adherence, the studied OACD, assessment measures, and the follow-up period.

Besides the aforementioned challenges for patients, also shifts in some traditional roles and responsibilities for HCPs are needed. HCPs should apply an approach that stimulates self-management in patients and their caregivers. Since OACD often have to be taken on a long-term basis, self-management support becomes predominant in the care for patients treated with OACD (Barlow et al., 2002; Galson, 2009; Weingart et al., 2008). A cross-sectional pilot study, investigating the relationship between patient-activation and self-management behaviour in patients treated with OACD, revealed that higher patient activation is a positive predictor for patient's confidence to manage side effects and to seek for help, but is however not associated with higher levels of adherence (Salgado et al., 2017). Patient activation was referred to as 'the individuals' knowledge, confidence, and ability to take up a role self-managing their health and healthcare' (Greene and Hibbard, 2012). Low levels of patient activation were associated with lack of insight in the mechanism of action of their medicines, in the causes of their cancer, and in the different treatment options. It also resulted in lack of knowledge concerning the prevention and treatment of side effects, and in lack of confidence in solving new problems during their therapy (Salgado et al., 2017).

In order to realize effective self-management support, a combined approach focussing on disease and symptom management, as well as on technical needs regarding the drug (e.g. dose regimen, side effects, missed doses), and on emotional and role management (e.g. certain hopes, anxiety) is needed (Institute of Medicine, 2004; Tadic et al., 2015). It is obvious that the HCPs involved in this patient support go far beyond the oncology team (i.e. oncologist, nursing staff and pharmacist) from the hospital (Bedell, 2003). Providing continuity of care by related primary caregivers (general practitioners, community pharmacists, home care nurses) in between hospital-based follow-up consultations, is also of high importance. However, a seamless collaboration between hospitals and primary caregivers is currently not stably implemented. Various barriers for this collaboration have been listed, such as lack of communication, absence of clear care plans, insufficient coordination of care, lack of guidelines, and insufficient information on care on the long-term (Aubin et al., 2012). Since OACD often involves different HCPs from primary and secondary care, recommendations with associated quality indicators regarding collaboration and communication between the different stakeholders are highly needed.

In oncology, various disease-specific recommendations and quality indicators (QI) e.g. for breast cancer (Chung et al., 2008), head and neck cancer (van Overveld et al., 2017), bladder cancer (Khare et al., 2017), and treatment-specific indicators e.g. for radiotherapy in breast cancer patients (Best et al., 2017) have been developed, mostly focusing on technical aspects (diagnosis, stageing, surgical aspects, choice of anticancer treatment). To our knowledge, there are currently no recommendations available on which key elements are important in the education and counselling of patients treated with oral anticancer drugs integrating all relevant aspects on coordination and continuity of care, communication with patients, initiation and follow-up of treatment, psychosocial needs, and involvement of family and caregivers.

Considering that quality of care for these patients is of high concern (May and Figgins, 2016), and given that the number of OACD will only increase, it is desirable to mutually agree on how education and counselling for these patients should be organized and performed. A first asset in this process is to define a set of key elements for the education and counselling process.

2. Aim

The aim of this study is to develop and build consensus on a set of key elements for the education and counselling of patients treated with oral anticancer drugs.

3. Methods

3.1. Design and methodology

A multi-method approach was used to develop the initial list of KE, and was followed by a Delphi-study. The construct of the initial list of KE was based on (1) a literature search, (2) semi-structured interviews with different stakeholders - patients and HCPs from primary and secondary care – and (3) input from domain experts. First, the initial set of KE was developed by the interdisciplinary research team (n = 4; pharmacy and nursing) in collaboration with domain experts (n = 4). The domain expert group was multidisciplinary and consisted of members all with more than ten years research and/or clinical experience (i.e. oncologist and advanced practice nurses) in counselling patients taking OACD and/or expertise in communication and patient self-management. Subsequently, consensus was built using a two-round Delphi-study (Fig. 1). The Delphi Technique is a well-placed method to obtain consensus in a target group of participants that is geographically dispersed and that have different backgrounds and fields of expertise (Keeney et al., 2011).

3.2. Development of the initial set of key elements

The literature search was performed by two researchers and aimed to identify specific elements of patient education and counselling in cancer care. The search was limited to papers published between 2005 (before, few OACD were marketed) and 2015 and was performed in PubMed® and Web of Science® combining "cancer care" (and synonyms) OR "oral chemotherapy" (and synonyms) AND "quality indicators" (and synonyms) OR "recommendations" OR "standards". Publications were

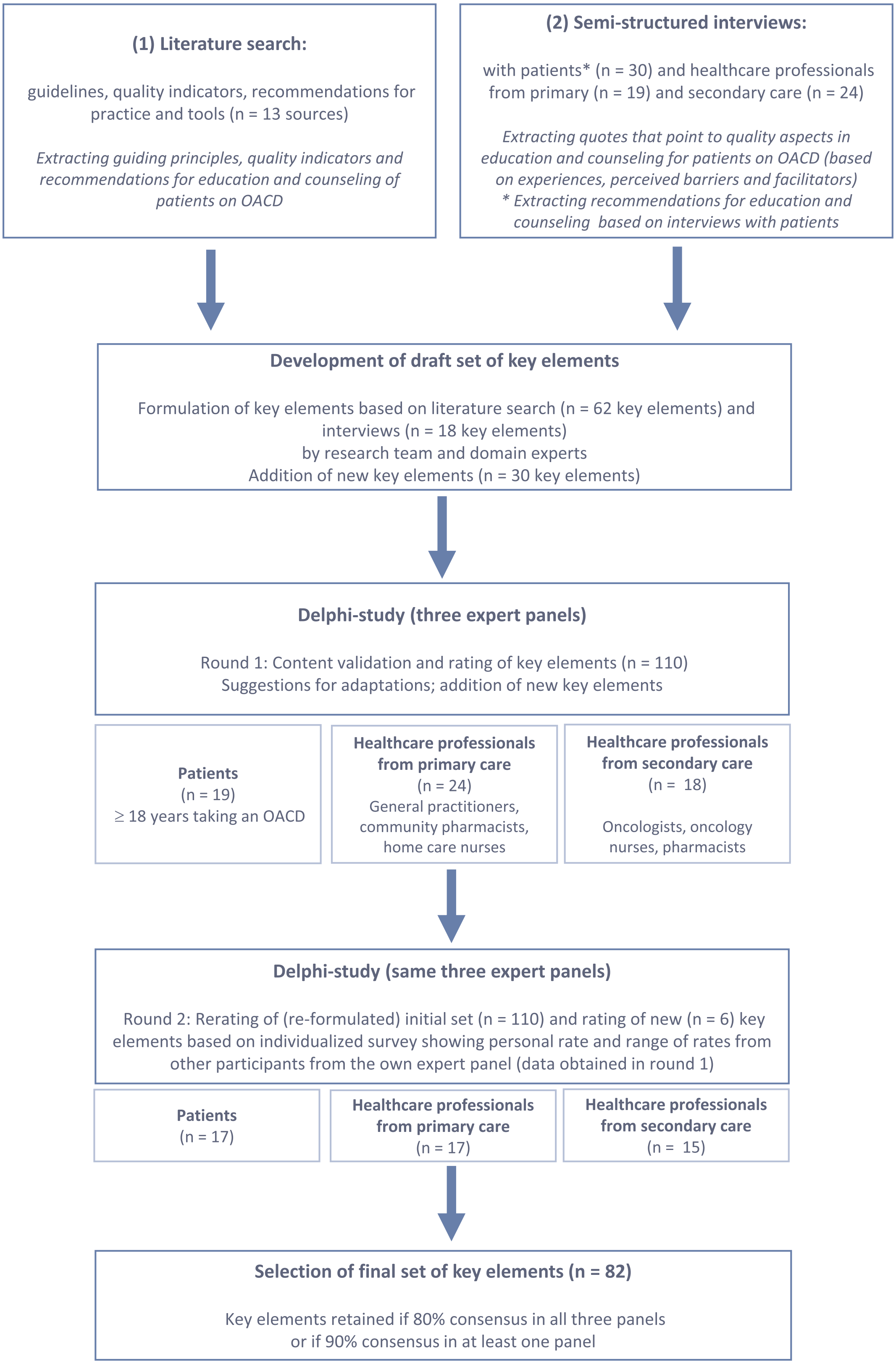

Fig. 1. Overview of the development of the initial set of key elements and Delphi-procedure for content validation and consensus-building.

taken into consideration if their main focus was a description of QI for cancer therapy or guidelines/recommendations for practice. Moreover, they had to list elements of education and counselling in general, for disease-specific cancer care or for oral anticancer therapies. Also grey literature (publications on relevant websites, e.g. National Comprehensive Cancer Network (NCCN) and American Society of Clinical Oncology (ASCO)) was taken into account.

Semi-structured interviews with HCPs from primary and secondary care focused on experiences, barriers and facilitators in all aspects of the care process for patients treated with OACD. Healthcare professionals (physicians, nurses and pharmacists) were recruited purposively in hospitals (n = 10) that participated in a prior multicentre observational study conducted by the research team. Interview guides were used covering a wide range of topics: experiences with providing care for patients treated with OACD, the process of patient education and counselling, how adherence is discussed, toxicity-management, interdisciplinary collaboration and collaboration between primary and secondary care. All semi-structured interviews were transcribed verbatim and analysed using inductive thematic framework analysis that integrates manifest content, supported by NVivo® software for qualitative research.

Insight in patients' perspectives on oral anticancer therapy was obtained from interviews performed as part of a larger research project that investigated factors influencing self-management and adherence during a treatment with tyrosine kinase inhibitors. Semi-structured interviews were performed using an interview guide including topics concerning attitudes towards the medication regimen, principles of self-management (fit OACD into daily life, adherence, coping with the treatment and its consequences), information received from HCPs and own research, social support and dealing with side effects. The findings from this study have been reported (Verbrugghe et al., 2016) and were used to develop a practical guide for HCPs with recommendations on how to support adherence and self-management in patients taking OACD (Verbrugghe et al., 2014). This set of recommendations was screened for possible items that could point to patient education and counselling in these patients.

To select and define candidate KE, a step-wise approach was used. First, two members of the research team listed possible elements from the literature search. Secondly, they checked transcripts from interviews with HCPs from primary and secondary care for any additional elements (quotes) that pointed to quality aspects in education and counseling of patients treated with OACD. Lastly, the practical guide with recommendations, based upon interviews with patients (Verbrugghe et al., 2014), was screened for elements that refer to KE that were not listed before. All findings from the literature and interviews were subsequently pooled by the full research team and transformed to KE in collaboration with the group of domain experts who were also allowed to add additional KE based on their expertise. Through an iterative process of discussions between domain experts and researchers until saturation of elements had occurred, the initial list of KE was built and structured into themes. The group of researchers and domain experts also payed attention to the formulation of the KE in a comprehensive and understandable way for patients. At the end of the development process, KE could either originate from literature, interviews, or the experts, whatever occurred first within the development process. Consensus on the content of the set of KE was subsequently built in a two-round Delphi-study. The details of the development of the set of KE can be found in Fig. 1.

3.3. Participants in the delphi process

Three different panels of participants were used to build consensus in the two-round Delphi-study: patients taking OACD, HCPs from primary care, and HCPs from secondary care. Patients aged 18 years and older currently following a treatment with one or more OACD were purposively recruited (1) by means of launch calls in Flemish patient associations and (2) at the oncology department of the Leuven University Hospital, Belgium. Patients following an adjuvant hormonal therapy (e.g. tamoxifen for 5 years) were excluded from the study. These therapies are more considered as chronic treatments and require a less frequent and intensive follow-up by HCPs. Oral anticancer drugs, such as tyrosine kinase inhibitors, are often indicated in a later stage of the disease (except for some hematological cancers) and are frequently administered in treatment cycles of 28 days. Hence, follow-up on a regular basis (in terms of progression of the disease, effectiveness of the treatment and toxicity profiles) should be provided.

Healthcare professionals (primary and secondary care) eligible for the study had to be actively involved in the care for patients treated with OACD and therefore had a perception on what KE for the education and counselling might be important. We also aimed to involve HCPs active in palliative care since many OACD are indicated in a palliative stage of the disease. Healthcare professionals from primary care (general practitioners (GP), community pharmacists and home care nurses) were purposively recruited by launch calls in different professional associations in Flanders. Healthcare professionals from secondary care (oncologists, oncology nurses, specialized and advanced practice oncology nurses and hospital pharmacists) involved in the care for patients treated with OACD, were purposively recruited in different Flemish hospitals that participated in prior research projects on oral anticancer drugs. Overall, 19 patients, 24 HCPs from primary care and 18 from secondary care participated in the first Delphi round. In primary care, three GPs, three pharmacists and one nurse dropped out after the first round; in secondary care one oncologist and two hospital pharmacists only completed the survey in round 1. Characteristics of participants in round two can be found in Table 2. Patients were treated with different OACD: abiraterone (n = 1), axitinib (n = 2), chloorambucil (n = 1), imatinib (n = 2), lenalidomide (n = 1), letrozol (n = 1), nilotinib (n = 1), pazopanib (n = 1), sorafenib (n = 2), temosolomide (n = 3), sunitinib (n = 1) and vismodegib (n = 1). Two of the participating home care nurses were actively involved in a palliative care network. The HCPs originated from all five Flemish provinces. In secondary care, HCPs from 10 different hospitals participated in both Delphi rounds (university/peripheral hospitals).

3.4. Data collection and analysis

The Delphi-study took place between November 2015 and February 2016 in two rounds. In Delphi round one, the list of potential KE was reviewed in an online survey (Limesurvey®). The link of this survey was distributed by e-mail to all participants who had confirmed to participate. All participants were asked to indicate to which extent the KE could contribute to adequate counselling and education of patients treated with OACD. Each KE was rated from (1) "barely", (2) "to a limited extent", (3) "to some extent", (4) "largely" to (5) "in a very large extent". For each theme, participants were free to comment or make adjustments to existing KE and to add new ones. Additionally, demographic data on participants were collected.

After round one, for each KE, graphs per panel of participants were drafted indicating the range of answers. In the second Delphi round, each participant received a link to the online survey together with a personalized summary document combining the graph per KE together with the individual answer. This allowed to position the personal answers to those of the panel. All initial KE were integrated in the survey together with the newly added KE. Participants were asked to rerate their own scores from round one; scores could remain the same or differ from round one. New KE were scored similarly as the KE in round one. The same rating options were used.

In both Delphi rounds, for each KE and for each panel of participants (patients – primary care - secondary care), the percentage of participants who rated the contribution of the element as 'largely' or 'in a very large extent' was calculated. Key elements were retained after round two if at least 80% of participants in all three panels rated the KE "largely" or "in very large extent". Even if not fulfilling this rule, elements were retained if 90% consensus was obtained in at least one panel of participants.

3.5. Ethical considerations

Ethical approval for the different parts of this project was obtained from the respective Ethics Committees. All participants were given written information regarding the aim of the study, had the opportunity to ask questions, and were informed about their right to cancel their participation at any time without giving any reason. Participants were informed that the interviews would be recorded and that all data – both from interviews and the Delphi procedure - would be handled confidentially.

3.6. Rigour

Different steps were taken to guarantee the rigour of the study. First, we ensured the quality of the initial set of KE by using different sources of data during the development process. Moreover, the initial set was formulated and reformulated in an iterative process by a group of experts with different backgrounds and expertise. Next, steps were taken to consider the potential issues related to Delphi studies (Keeney et al., 2006; Keeney et al., 2001). To respond to the appropriate selection of participants and low response rates, we recruited participants in different Flemish regions and regularly sent reminders to ensure the questionnaires were completed. Anonymity was guaranteed in all steps of the Delphi-study by sending the link of both surveys to participants individually and using anonymized graphs in the individualized document. The different members of the research team ensured the rigourous development of the questionnaire by critically reviewing the web survey. Finally, the full research team was involved in 1) the analysis and development of the individual documents per participant after round 1, and 2) the decision on the level of consensus to withhold KE by means of meetings discussing the results. Hence, the rigour approach in data analysis and reporting was ensured.

4. Results

4.1. The initial set of KE: item generation

The literature search (Fig. 1) revealed research on the development and validation of QI in generic and indication-specific cancer settings. Furthermore, quality measures specific for OACD were found in the Quality Oncology Practice Initiative (QOPI) program from ASCO (ASCO, 2018). In total, the literature search yielded 64 possible items (including the results from the interviews with patients as reported in the practical guide (Verbrugghe et al., 2014), to use in the formulation of KE. These KE including their supporting references are summarized in Table 1. The structure mostly used in literature to divide the QI was based on the six dimensions of patient-centred care from the Institute of Medicine (IOM) (Institute of Medicine, 2001): respect for the patient's values, preferences, and expressed needs; information, communication and education; coordination of care; physical comfort; emotional support; and involvement of family and friends (Ouwens et al., 2010; Uphoff et al., 2012; van Overveld et al., 2017; Williams et al., 2018). The classification of our set of KE was based upon these domains and is outlined in Table 1. Theme A covers KE on the coordination of the care process (including continuity of care). Key elements on communication were divided into two themes (B1 and B2) in order to clarify for HCPs that effective self-management support depends both on what and how it is communicated (Elissen et al., 2013; Morgan et al., 2017). Due to the focus on OACD, two themes concern KE on patient education: initiation of treatment (C) and follow-up (D). Given the importance of addressing both medical and emotional needs of patients and their family in order to obtain effective self-management, KE on psychosocial support and involvement of family were grouped in theme E and F. The interviews with HCPs from primary and secondary care resulted in another 19 key elements and based on the input of experts, 27 key elements were added. After the development process, an initial set of 110 KE was obtained (Table 1).

4.2. The Delphi procedure

After round one, 80% consensus in all groups of participants was reached for 23/110 kE. For none of the KE in the themes on "psychosocial support" and "involvement of family and friends" consensus was reached. Based upon the comments participants made in the first round, six KE were reworded with the purpose of further clarification and six new KE were added. Four KE were added to the theme "coordination of care", one to theme "patient contacts: style", and one to theme "involvement of family and friends". This resulted in a set of 116 potential KE for validation in round two.

In round two, 80% consensus in all three panels was reached for 51/116 kE (43,9%). After applying the 90%-rule, 31 additional KE were considered as being valid. A detailed calculation for all KE can be found in Table 3. Approximately half of the additionally retained KE (15/31) belonged to the theme "medication counselling at the start" and "follow-up of the therapy". From the six newly identified KE, four were retained after round two. Healthcare professionals from secondary care reached ≥80% consensus for 102 KE after the second round. For only 60 KE both HCPs from primary and secondary care reached ≥80% consensus.

From the final list of 82 kE, 45 (54,8%) were based on findings from the literature and guidelines, 18 (22,0%) on input from experts and 15 (18,3%) on interviews with patients or HCPs from primary and secondary care.

5. Discussion

In this study, a set of 82 KE for the education and counselling of patients treated with OACD was developed. The KE are structured in six themes, in line with the IOM domains of patient-centred care, and aim to support self-management. This set can now be used by oncology teams to build clinical pathways or enhance care processes.

In oncology, various Delphi-studies have been performed to develop QI (disease-specific, treatment specific, palliative care etc.) (Chung et al., 2008; van Overveld et al., 2017; Khare et al., 2017; Best et al., 2017; Nakazawa et al., 2016; Williams et al., 2018). Similarly to the development and review process described in these studies, our initial list of KE on OACD was based upon existing literature, which renders its international relevance. In our search, we specifically focused on existing QI and guidelines. The retrieved QI and guidelines were built from existing evidence and/or clinical practice, which, to our opinion, made them highly applicable for the development of our set of KE. We did not look for specific patient education intervention studies that aimed to assess their efficacy and applicability. Although such studies are highly relevant, the papers reporting on the outcomes usually do not describe concrete information on how to perform patient education and counselling, which was the main focus of our set of KE. Additionally, we included information from interviews with HCPs and patients and input of domain experts. Interviews were also taken into account by Ouwens et al. (2010). It is important to point out that we followed a step-wise approach – literature, interviews with HCPs, interviews with patients - in finding evidence that pointed towards KE. It is clear that many KE were not only supported by literature, but also by data from interviews with HCPs and/or patients. The development process pursued until saturation of KE had been obtained. The initial set was subsequently reviewed in a two-round Delphi study with three panels including HCPs from primary and secondary care and patients – the key players in the care process. The importance of the involvement of and even partnership with patients with cancer in the development of guidelines and QI has previously been stressed (Karazivan et al., 2015; Ouwens et al., 2010). However, in none of the aforementioned studies, representatives from patients and HCPs from primary and secondary care were involved. The involvement of the three panels in our study is therefore unique and resulted in a clear focus on (1) continuity of care, (2) interdisciplinary communication and collaboration, and (3) patient participation.

The structure used for the classification of the KE is based upon the concept of patient-centred care, published by the IOM. This classification was also used in other papers (Ouwens et al., 2010; Uphoff et al.,

Table 1

Overview of the key elements per theme with reference to the primary source (literature, interviews with healthcare professionals, domain experts, practical guide based on patient interviews.

No.	Final formulation of key elements	Primary source code[a]	Reference	Description from reference/Quote illustrating the key element
THEME A. Coordination of care: framework, commitment and cooperation between different healthcare professionals				
A1	Patient contacts take place in a room with sufficient privacy (i.e. a separate interview room, no third parties present at the interview).	L[b]	(Uphoff et al., 2012); QI	Providing a room with adequate privacy
A2	Patient contacts start at the agreed time.	INT[c]	Interview HCPs secondary care	“You're always running late during your consultations, people keep on waiting” Oncologist
A3	The healthcare professionals take sufficient time for a proper interview, in which every aspect of support, that is relevant at the time, is covered.	L	(Uphoff et al., 2012); QI	With enough time for an accurate conversation
A4	The healthcare professionals arrange for an adequate number of contact moments (responding to the needs of the individual patient and/or as needed for medical follow-up).	INT	Interview HCPs secondary care	“I think it's important that patients come back on a regular basis, especially to follow-up on side effects …” Hospital pharmacist “Patients have to come regularly for consultations, because in the first 2-3 months you are searching for an adequate dose that is appropriate with regard to side effects. That is how it is. After a few months you know that the patient can support that dose; there are some exceptions of course, but mostly you can keep that dose. In the first period you need to see the patient every two weeks.” Oncologist
A5	The healthcare professionals emphasize [g] that they are always available for questions or concerns, and provide the necessary contact details to the patient or family (including hours during which contact can be made).	L	(Ouwens et al., 2010); QI (ASCO, 2018); QI	Patient can reach the specialist between consultations Oral chemotherapy education provided prior to the start of the study: clinic contact instructions
A6	All healthcare professionals at the hospital who are involved in oral anticancer therapies are guaranteed access to relevant sources of information about it (product information, instructions on administration, expected side effects, interactions, etc.).	DE[d]		
A7	Prior to contact with the patient, the healthcare professionals familiarize themselves with the prescribed anticancer medication.	DE		
A8	Prior to contact with the patient, the healthcare professionals at the hospital consult the multidisciplinary patient file so that they are able to make a proper assessment of the patient's situation.	DE		
A9	After each patient contact, the healthcare professionals at the hospital report in a shared multidisciplinary patient health record, allowing efficient exchange of information.	L	(Sada et al., 2011); qualitative study	Physicians believed that the electronic health record improved communication and efficiency within their hospital system. “I don't have to contact oncologists too much about basic things, electronic notes are all accessible.”
A10	The therapy plan is shared between all healthcare professionals, both in primary care and in the hospital, and each healthcare professional responsible for reporting any changes.	INT	Interviews HCP primary care	“The pharmacist has to provide an actual therapy plan to the patient. Everything starts with [the fact that] they [from the hospital] need to inform us, that they provide us with exact information when patients leave the hospital, and that this [oral anticancer drug] is part of the information. When patients now leave the hospital, this [oral anticancer drug] cannot be found in the information”. Community pharmacist. “I think yes, medication, that is what the pharmacist knows. But other supplements, as well as teas, and other things [not], that is now very important. With the shared therapy plan that is now being discussed, we will try to transfer information, and mention ‘this is also taken by the patient, as well as this, and that’ …. ” Home care nurse.
A11	The multidisciplinary team discusses what follow-up is called for and which healthcare professional is responsible for it; this is recorded in the patient file.	L	(Borras et al., 2014); research paper	Multidisciplinary teams (MDTs) are an alliance of all medical and healthcare professionals related to a specific tumour disease whose approach to cancer care is guided by their willingness to agree on evidence-based clinical decisions and to co-ordinate the delivery of care at all stages of the process, encouraging patients in turn to take an active role in their care.
A12	The general practitioner is involved in choices concerning the treatment, for instance via the Multidisciplinary Oncology Consultation (MOC). (This is a meeting focusing on the diagnosis and treatment of cancer patients, whereby at least three doctors with different specializations are present.).	INT	Interview HCP secondary care	“Sometimes also with the GP, that we first have contact with the GP, to ask how he/she perceives it [the therapy]. Does he/she think the patient can further manage any [further] therapy?” Oncologist
A13	The healthcare professionals show that they collaborate with one another.	L	(Borras et al., 2014); research paper	Firstly, information on multidisciplinary team organisation should be provided to patients to promote a greater understanding of the specific collaborative approach.

(*continued on next page*)

Table 1 (*continued*)

No.	Final formulation of key elements	Primary source code[a]	Reference	Description from reference/Quote illustrating the key element
A14	At the start of the treatment, primary care healthcare professionals are informed by the hospital treatment team about the oral anticancer medication, with attention for dosage, correct use, expected side effects, interactions and medication to be avoided.	L	(National Health Service, 2014); recommendations	Ensure appropriate communication to patient's GP and referring consultant about the medicines, ensuring the GP is clear on the role they play in managing patient.
A15	Primary care healthcare professionals receive the necessary contact details, so that they can easily contact the hospital treatment team.	INT	Interview with HCP from secondary care	"And that they [GPs] preferably contact us when something new… So, we mention this to our patients; we give contact information, we have our own business cards, and we give them for the patient and also for the GP." Oncologist
A16	Primary care healthcare professionals provide follow-up for the patient and are a point of contact for care issues and needs related to the oral anticancer medication.	INT	Interview with HCP from secondary care	"And also the oncologist-GP and patient-GP relationship is important. I always try to involve the GP as much as possible; for instance that the follow-up of toxicities is performed by the GP." Oncologist
A17	Primary care healthcare professionals are aware of the situations in which they must refer patients to the hospital treatment team.	DE		
A18	The healthcare professionals involve the palliative support team in the care process if necessary and when asked for by the patient.	DE		
A19	All healthcare professionals who support patients with oral anticancer medication have been trained to appropriately interact with this target group, including discussing medication adherence and promoting self-management.	DR II [e]		
A20	The clinical pharmacist is involved in the choice and the monitoring of treatment, for instance via the 'Multidisciplinary Oncology Consultation' (MOC) (This is a meeting focusing on the diagnosis and treatment of cancer patients, whereby at least three doctors with different specializations are present.).	DR II		
A21	Healthcare professionals who can be contacted in emergencies at night or in the weekend, have access to the patient's file.	DR II		
A22	The patient has easy access to his or her medical record.	DR II		
THEME B. Contact with patients: style				
B1	The healthcare professional takes into account a patient's coping capacity (the extent to which a patient is able process the information provided) and the patient's information needs, and adjusts the information accordingly.	DE		
B2	The healthcare professional takes into account the capacity of the patient to understand health information, and adjusts the information accordingly.	L	(Uphoff et al., 2012)QI	Adjusting information to the condition of the individual patient Adjusting information to the language skills of the patient and, when necessary, providing information in the native language of the patient
			(Neuss et al., 2013) recommendations	Patient education materials should be appropriate for the patient's reading level/ literacy and patient/caregiver understanding.
B3	The healthcare professional takes into account the patient's language skills, if needed s/he provides the information in the patient's mother tongue (if necessary by means of an interpreter)	L	(Lorenz et al., 2009); QI	If a patient is newly diagnosed with cancer and speaks a primary language that the physician does not speak fluently, then the diagnosis should be communicated with the assistance of a translator, because a cancer diagnosis has important implications for the patient who deserves the opportunity to understand comprehensively and ask questions in his or her native language.
B4	The healthcare professional provides the most important information first.	L	(Uphoff et al., 2012); QI	Giving the most important information first.
B5	The healthcare professional explains medical terminology to the patient.	L	(Uphoff et al., 2012); QI	Explaining medical terminology to the patient
B6	The healthcare professional poses open-ended questions (questions that invite sharing more).	L	(Uphoff et al., 2012); QI	Asking open-ended questions
B7	The healthcare professional leaves enough opportunity for the patient to ask questions at any time.	L	(Ouwens et al., 2010) QI	Patient had opportunities to ask questions
B8	The healthcare professional repeats the information and summarizes the most important points.	L	(Uphoff et al., 2012); QI	Summarizing and repeating information
B9	The healthcare professionals do not provide contradictory information.	L	(Ouwens et al., 2010) QI	Patient received contradictory information
B10	The healthcare professional informs the patient honestly and completely, whereby no information is withheld.	INT	Interviews HCPs secondary care	"I think that sincerity and honesty, …The patient needs to feel that you are honest, that you tell everything to him/her." Oncologist
B11	The healthcare professional checks whether the patient has understood all the information, if necessary the information is repeated and/or a second interview is planned with the patient	L	(Uphoff et al., 2012); QI (Neuss et al., 2013) recommendations	Check if information is understood Documentation should include patient feedback reflecting understanding and engagement.

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Table 1 (*continued*)

No.	Final formulation of key elements	Primary source code[a]	Reference	Description from reference/Quote illustrating the key element
B12	Where possible, the healthcare professional provides information leaflets or refers to information on a website.	L	(Neuss et al., 2013) recommendations	Before initiation of a chemotherapy regimen, each patient is given written documentation
			(Uphoff et al., 2012); QI	Provide a list of sources of information
			(Ouwens et al., 2010) QI	Patient received written information
B13	*New: After a bad news consultation, the patient is given time to process this information and is to ask any questions to the healthcare professional later on.	DR II		
THEME C. Contact with patients: content				
C1	The content of the patient contact is partly defined by what is important to the patient at that moment (problems, complaints, questions, needs).	DE		
C2	Already at time of diagnosis, the healthcare professional provides sufficient information.	DE		
C3	The healthcare professional offers information about the disease.	L	(Neuss et al., 2013) recommendations	Information regarding his or her diagnosis
			(Lorenz et al., 2009) QI	Because effective communication about diagnosis, prognosis, and care plans is important to high-quality cancer care.
C4	The healthcare professional provides information about the prognosis (prediction of the further progression of the illness).	L	(Lorenz et al., 2009) QI	Because effective communication about diagnosis, prognosis, and care plans is important to high-quality cancer care, …
C5	The healthcare professional provides information about the examinations that the patient will have to undergo, as well as the significance of their results and their impact on additional therapy.	INT		"And then I arrange with the patient, so I plan for the patient, every two weeks you come back to me, and within three months we will perform a scan." Oncologist
C6	The healthcare professional provides information about what the patient can do to prevent or to alleviate certain complaints (that are related to the condition).	DE		
C7	The healthcare professional promotes self-care and provides the relevant information and support.	L	(Uphoff et al., 2012); QI	Depending on the individual patient, the healthcare provider should stimulate self-management and offer proper information and support
C8	The healthcare professional involves the patient in choices related to the treatment.	L	(Ouwens et al., 2010) QI	Specialists shared the decision making with the patient
C9	The healthcare professional provides information about the treatment's objective.	L	(Neuss et al., 2013) recommendations	Before initiation of a chemotherapy regimen, each patient is given written documentation, including, at mimimum (…) goals of therapy
			(Ouwens et al., 2010) QI	Specialists discussed aim and follow-up of the treatment with the patient
C10	If the proposed oral medication is only available in the context of a study, the healthcare professional supports the patient in every step that needs to be taken to participate in this study (including thoroughly informing the patient about the study).	INT		"It is a patient participating in a clinical trial, she is using Afinitor, and that [the therapy] goes very well. I need to see her because of the study, but that [the therapy] goes very well, so I wonder whether it is really necessary to see her every time. But all the others are also seen every month." Oncologist. "I noticed that it was easy for patients to contact me as a study nurse, and that they did so." Hospital nurse
C11	The healthcare professional informs the patient about symptoms that could point to progression of the disease.	L	Stiefel & Razavi (2006)	Progression of disease is another crucial moment in the physician–patient communication. When progression occurs, patients—sometimes for the first time—are preoccupied with the outcome of their disease.
C12	The healthcare professional informs the patient early on about the possible (treatment) options if there would be no response to the treatment or if it would not be possible to continue the treatment due to side effects.	INT		"And then I try, during a bad news consultation, to find future perspectives, euhm, so that you can say to the patient 'look, it is a progressive disease, but there are more options'. And those options can be another therapy, but it can also be a 'wait and see' attitude, or not to start a [new] therapy anymore." Oncologist
C13	Early on, the healthcare professional discusses the options for further care planning and end-of-life care, including palliative care.	L	(Uphoff et al., 2012); QI	The healthcare provider should emphasize that the patient will receive optimal palliative care and that the healthcare provider will not leave the patient to his/her fate.
C14	The healthcare professional offers information about palliative care and how the palliative care team operates, in such a way that the patient understands that this does not necessarily mean 'the end'.	L, INT	(Uphoff et al., 2012); QI	The healthcare provider should emphasize that the patient will receive optimal palliative care and that the healthcare provider will not leave the patient to his/her fate. "You present the full oncology team, that includes also the palliative expert". Oncologist
THEME D. Medication counselling at the start of the oral anticancer therapy: intake, adherence and adverse events				
D1	The healthcare professional gives information about the mechanism of action of the oral anticancer medication.	DE		
D2	The healthcare professional is careful about communicating that the 'best possible' medication is being started at the 'best possible' dose.	DE		

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Table 1 (*continued*)

No.	Final formulation of key elements	Primary source code[a]	Reference	Description from reference/Quote illustrating the key element
D3	The healthcare professional provides clear instructions about the use of the oral anticancer medication.	L	(Neuss et al., 2013) recommendations	Patient education includes administration of oral chemotherapy
D4	The instructions for administering the oral anticancer medication are clearly mentioned on the label.	L	Neuss et al., 2013, recommendations	Chemotherapy drugs are labeled immediately upon preparation, including (oral agents): administration instructions
D5	The healthcare professional explains why correct administration of oral anticancer medication is important for the treatment results.	P [f]	(Verbrugghe et al., 2014, 2016)	Explain why correct administration of the medication is important and what the result could be of inadequate self-management. In this way, patients build basic knowledge on their treatment as a basis for achieving an adequate level of self-management.
D6	Together with the patient, the healthcare professional examines how the medication can best be incorporated in the patient's day-to-day life.	P	(Verbrugghe et al., 2014, 2016)	At the start of the treatment, time should be spent to determine how the administration can be incorporated in the patient's day-to-day life.
D7	The healthcare professional investigates how a patient, who already has to take several medications, views the combination of his/her present treatment with the oral anticancer medication.	P	(Verbrugghe et al., 2014, 2016)	Healthcare professionals should be attentive for existing anxieties on the harmful effects of combining a large amount of drugs. Patients should be reassured and informed.
D8	The healthcare professional provides the patient with a clear medication plan, in which other medication is also mentioned (if applicable).	INT, L	Interview HCPs secondary care	"I don't know if they receive a therapy plan on paper, I have no clue idea. That could also contribute [to adherence]. If there is only oral communication, they [the patients] have nothing to rely on. They often have a copy of the prescription, but there is only mentioned, e.g. 2 × 400 mg Nexavar per day. Yes, but when do they have to take it? Before meal or with meal? In the morning at 8 o'clock or on an empty stomach, is that at 10 o'clock or at 16 h in the afternoon? That is not written on the prescription. I don't know if the oncology department has provided something as a therapy plan that is provided to the patient, so that they have something to rely on." Hospital pharmacist
			Neuss et al., 2013, recommendations	Staff review and document the patient's current medications, including over-the-counter medications and complementary and alternative therapies.
D9	The healthcare professional provides the patient with sufficient information about the medication plan so that it can be correctly and strictly followed.	INT	Interview HCPs secondary care	"I think to develop therapy plans [could also be my task]. It think this is often a problem. The physicians think 'this three times a day, that four times a day; this with meal, that before meal', while a pharmacist can say 'this you have to take, how could that be done in practice'; he overviews the whole therapy, and does not consider it as separate pills. To help the patient: 'when do you take breakfast? Do you take breakfast'?" Hospital pharmacist.
D10	The healthcare professional informs the patient about what s/he must do if s/he has forgotten to take one or more doses.	L	(ASCO, 2018); QI	Oral chemotherapy education provided prior to the start of therapy: Missed doses
			Neuss et al., 2013, recommendations	Patient education includes: a plan for missed doses
			(National Health Service, 2014); recommendations	Ensure the patient understands what to do in the event of missing one or more doses
D11	The healthcare professional informs the patient about what s/he must do if s/he has vomited after taking the oral anticancer medication.	L	(National Health Service, 2014); recommendations	Patient must ensure that they fully understand what to do in case of vomiting after taking a dose
D12	The healthcare professional provides oral and written information about the treatment's possible risks and side effects.	L	Neuss et al., 2013, recommendations	Before initiation of a chemotherapy regimen, each patient is given written documentation, including, at minimum: information on possible short- and long-term adverse effects, including infertility risks
			(Lorenz et al., 2009); QI	If a patient with cancer undergoes chemotherapy, then before chemotherapy, he or she should be informed about the risks and benefits of treatment, including likely symptoms and side effects
			(National Health Service, 2014); recommendations	Ensure patients know likely adverse effects and what to do about them
			(ASCO, 2018); QI	Oral chemotherapy education provided prior to the start of therapy: Toxicities
			(Ouwens et al., 2010) QI	Patient knows which side effects to be aware of
D13	The healthcare professional provides oral information on how the patient can deal with frequently occurring side effects.	L	(National Health Service, 2014); recommendations	Ensure patients know likely adverse effects and what to do about them
D14	In order to be able to cope with less frequently occurring side effects, the healthcare professional refers to a leaflet mentioning all possible side effects, and to the possibility of telephone contact.	DE		
D15	The healthcare professional informs the patient about the symptoms and complaints for which s/he (urgently) has to contact the doctor or nurse.	L	Neuss et al., 2013, recommendations	Before initiation of a chemotherapy regimen, each patient is given written documentation, including, at minimum: Regimen- or drug-specific risks or symptoms that require notification and emergency contact information including How to contact the practice or organization, symptoms that should trigger a call; who should be called in specific circumstances (oncologist or other provider).

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Table 1 (*continued*)

No.	Final formulation of key elements	Primary source code[a]	Reference	Description from reference/Quote illustrating the key element
D16	The healthcare professional provides the patient with information on what s/he is not allowed to eat during the treatment of his/her oral anticancer medication.	L	Neuss et al., 2013, recommendations	Patient education includes: possible drug/drug and drug/food interactions
D17	The healthcare professional provides information about the fact that not all medication can be taken together with the oral anticancer medication and encourages the patient to report the use of any medication (including food supplements and alternative health products) to the healthcare professionals concerned.	L	Neuss et al., 2013, recommendations	Patient education includes: possible drug/drug and drug/food interactions
D18	The healthcare professional informs the patient about which vaccines can be administered during the treatment and some time thereafter, and which cannot be administered.	DE		
D19	The healthcare professional informs the patient about safe handling and the storage of the oral anticancer medication.	L	(National Health Service, 2014); recommendations	Ensure patients know principles of safe handling, storage and disposal
			Neuss et al., 2013, recommendations	Patient education includes: the storage, handling, preparation, administration, and disposal of oral chemotherapy.
D20	The healthcare professional ensures the patient understands that the medication is only intended for him/her and may not be taken by others.	L	(National Health Service, 2014); recommendations	Ensure patients know principles of safe handling, storage and disposal
			(Kav et al., 2010) recommendations	Keep the pills/tablets away from children and pets and in a childproof container.
THEME E. Monitoring of treatment: usage, adherence and adverse events				
E1	During follow-up consultations, the healthcare professional's starting point is the information that was discussed at the start of the treatment and/or during earlier follow-up interviews.	DE		
E2	The healthcare professional inquiries into the symptoms related to the illness and the treatment.	L	(Lennes and Lynch, 2009) QI	Patients reported provider attention to physical symptoms
			Neuss et al., 2013, recommendations	The practice/institution evaluates and documents treatment-related toxicities using standard definitions or criteria selected by that practice/institution.
E3	The healthcare professional asks the patient how s/he describes his/her quality of life and what impact the treatment has on this quality of life.	DE		
E4	The healthcare professional inquiries what the patients' impressions are of (the effects of) the medication (How does the patient perceive his/her medication and what does s/he think about it?).	DE		
E5	If relevant, the healthcare professional checks the dose of the oral anticancer medication against the present weight and the kidney and liver functions.	DE		
E6	The healthcare professional explains to the patient why, in certain situations, it is necessary to reduce the dose and finds out how the patient feels/thinks about this.	P	(Verbrugghe et al., 2014, 2016)	Patients should know that a dose reduction does not necessarily lead to less efficacy of the OACD.
E7	After a dose reduction, the healthcare professional plans an evaluation moment to establish the impact on side effects and to discuss any concerns or problems.	P	(Verbrugghe et al., 2014, 2016)	After a dose reducation, a follow-up consultation should be planned as soon as possible. This will give the patient in time information on tumor growth after dose reduction.
E8	During the patient contact, the healthcare professional offers information about any possible change in medication.	INT		"First, the physician will explain "Listen, we will change the therapy, we will switch to that medication." Hmm. And he will also shortly explain what it does, why it is chosen, how it works" Hospital nurse
E9	Each time the medication is changed, the healthcare professional provides the patient with a new medication plan.	INT		"Yes we ask (patients) to take (the therapy plan) to the GP, and if he changes something we ask to adapt it. It should be updatet he. So that we are also informed. You can't do anuthing with a therapy plan that is not correct." Community pharmacist
E10	During each patient contact, the healthcare professional checks the patient's compliance with the therapy.	L	(ASCO, 2018); QI	Oral chemotherapy monitored on visit/contact following start of therapy: Medication adherence assessed
			Neuss et al., 2013), recommendations	Monitoring and assessment: The practice/institution maintains a written policy and/or procedure to complete an initial assessment of patients' adherence to oral chemotherapy
E11	The healthcare professional actively inquires how the patient takes his/her medication and what potentially risky situations cause him/her to forget to take it.	DE		
E12	The healthcare professional discusses with the patient how s/he sees therapy compliance and adjusts his/her support accordingly.	DE		
E13	The healthcare professional continuously encourages the patient to be adherent, with attention and respect for the patient's individuality and freedom.	DE		

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Table 1 (*continued*)

No.	Final formulation of key elements	Primary source code[a]	Reference	Description from reference/Quote illustrating the key element
E14	If the adherence of patients with oral anticancer medication is insufficient, the healthcare professional discusses the issue and works with the patient to find a solution.	L	(ASCO, 2018); QI	Oral chemotherapy monitored on visit/contact following start of therapy: Medication adherence addressed
E15	The healthcare professional encourages the patient to report any event of not taking the oral anticancer medication.	DE		
E16	If relevant, the healthcare professional inquires what the rest period (between two treatment periods) means for the patient and how difficult resuming the medication is for him/her.	P	(Verbrugghe et al., 2014, 2016)	Ask the patient what a rest period in the treatment means to him/her. Recognize and discuss that it can often be difficult to resume the treatment after a rest period.
E17	During patient contact, the healthcare professional will map and follow up the seriousness and impact on daily life of any side effects.	L	(Uphoff et al., 2012), QI	The healthcare provider should make an inventory of complaints and problems that hinder the patient, search for causes, educate the patient on this subject, and start medical or nonmedical treatment with use of relevant medical disciplines.
			(ASCO, 2018); QI	Oral chemotherapy monitored on visit/contact following start of therapy
E18	The healthcare professional encourages the patient to report side effects and continues to monitor these.	P	(Verbrugghe et al., 2014, 2016)	Encourage the patient to report sides effects and make clear to the patient why it is important to report them honestly.
E19	In the case of side effects, the healthcare professional attempts as far as possible to ease or tackle the symptoms.	L	(Ouwens et al., 2010); QI	Patient got support to control physical complaints
			Neuss et al. (2013), recommendations	The policy includes, at minimum, patient assessment for adherence and toxicity at each clinical encounter at the practice/institution, as well as a plan for clinical staff to address any issues identified.
E20	The healthcare professional openly communicates about side effects that are difficult to manage, both by the patient and by the healthcare professional.	DE		
E21	For each new prescription, the general practitioner checks whether the new medication may be combined with the oral anticancer medication, and if in doubt s/he contacts a healthcare professional at the hospital.	INT	Interview HCPs secondary care	"I also think checking drug-drug interactions [could be a role for the GP]. Because the GPs start new things… Antibiotics (ciprofloxacin, clarithromycin, …) that give a real risk for drug-drug interactions." Hospital pharmacist
E22	For each new medication (both prescription and OTC), the pharmacist checks whether the new medication may be combined with the oral anticancer medication, and if in doubt s/he contacts a healthcare professional at the hospital.	DE		
THEME F. Psychosocial support: support of the patient and alertness to anxiety and depression				
F1	The healthcare professional pays attention to the impact of the illness and the treatment on the patient's life, roles and relationships.	DE		
F2	At the time of a bad news consultation with a doctor, an oncology nurse is present or available afterwards for additional emotional support.	DE		
F3	The healthcare professional pays attention to the degree of self-management, in particular with high-risk groups such as single and/or older patients, and offers extra support if necessary.	P	(Verbrugghe et al., 2014, 2016)	Healthcare professionals should be extra alert for the level of self-management and the need for additional support in single or older patients.
F4	The healthcare professional provides the patient with psychosocial support, even in between two consultations.	L	(Ouwens et al., 2010); QI	Patient received emotional support from nurses and specialists if needed
F5	The healthcare professional checks the patient's feelings and experiences to find out how the patient is coping with his/her illness and treatment, and coordinates the care accordingly.	L	Neuss et al. (2013), recommendations	Assessment regarding psychosocial concerns and need for support, with action taken when indicated.
			(Ouwens et al., 2010); QI	Patient was asked whether he had psychological complaints
F6	If necessary, the healthcare professional refers patients with psychosocial problems to specialist healthcare professionals.	L	(Uphoff et al., 2012); QI	The healthcare provider should gather information on the psychosocial and emotional health status of the patient on important moments in the process of care and adequately refer to specialists, depending on the diagnosed problems.
			Neuss et al. (2013), recommendations	The practice/institution maintains referral resources for psychosocial and other supportive care services.
F7	During the contact moments, the healthcare professional enquires specifically about anxiety and is alert to signals that point to this.	L	Neuss et al. (2013), recommendations	Assessment regarding psychosocial concerns and need for support, with action taken when indicated. Documentation of psychosocial concerns may include copy of distress, depression, or anxiety screening form in the chart; patient self-report of distress, depression, anxiety, …
		P	(Verbrugghe et al., 2014, 2016)	Be aware that patients can be anxious.
F8	The healthcare professional discusses the options to cope with anxiety with the patient.	L	(Uphoff et al., 2012); QI	The healthcare provider should gather information on the psychosocial and emotional health status of the patient on important moments in the process of care and adequately refer to specialists, depending on the diagnosed problems.
F9	If the patient finds it difficult or is unable to manage his/her anxiety, the healthcare professional will discuss with the patient the options of supplementing emotional support with medication.	L	(NCCN, 2018) guidelines	Consider medications to manage symptoms

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Table 1 (*continued*)

No.	Final formulation of key elements	Primary source code[a]	Reference	Description from reference/Quote illustrating the key element
F10	The healthcare professional finds out what patients look forward to and which hope and perspectives they cherish.	DE		
F11	The healthcare professional enables hope, without denying the reality of the disease and the prognosis (prediction about the further progress of the disease).	P	(Verbrugghe et al., 2014, 2016)	Hope is often a mechanism for patients to carry on. Do not disprove this hope In case you know patients are aware of the situation. Hope should be confirmed as hope and not as a fact.
F12	During contact with patients, the healthcare professional acknowledges that waiting for examination results can be frustrating.	INT	Interview HCPs secondary care	“[I agree that it can generate stress]. Because that patients know, it is now or never. In six weeks, overall scan, if that is not good, it is over, you know. […]. They are afraid, you know” Oncologist.
F13	The healthcare professional offers the patient information about patient organisations, so that s/he can get in touch with fellow sufferers to share experiences.	DE		
F14	The healthcare professional provides the patient with information about combining his/her disease with professional activities and hobbies.	DE		
F15	The healthcare professional assists the patient with the financial aspects (insurance documents, certificates) of the treatment and if necessary refers the patient to the appropriate social services.	DE		
THEME G. Involvement of family and friends				
G1	The healthcare professional encourages the patient to take someone along to the consultation.	L	(Uphoff et al., 2012); QI	Involving family and friends in the conversation, by inviting the patient to bring someone to appointments
G2	The healthcare professional involves family and friends in the conversation.	L	(Uphoff et al., 2012); QI	Involving family and friends in the conversation, by inviting the patient to bring someone to appointments
G3	The healthcare professional offers family and friends the opportunity to ask questions.	L	(Ouwens et al., 2010); QI	Family and friends had opportunities to ask the nurses questions
G4	Family and friends who are closely involved, receive sufficient information about the use of the oral anticancer medication, including information about dealing with side effects.	INT		“About intravenous treatment, everybody knows, ‘oh, it is chemotherapy; the person will be ill, nauseous,…’ It is sometimes more accepted than with per os medication, so I think for the healthcare sector, there is an important task to mention it to the patient and to also inform the family, if they are present.” Hospital nurse
G5	The healthcare professional encourages efforts made by the carer in the context of the patient's care.	DE		
G6	If desired by closely involved family and friends, the healthcare professional offers psychosocial support.	L	(Uphoff et al., 2012); QI	The care providers should gather information on the psychosocial and emotional health status of family and friends of the patients and adequately refers to specialists, depending on diagnosed problems.
G7	The healthcare professional offers advice or helps the patient to inform their family and friends.	DE		
G8	The healthcare professional inquires with family and friends who are closely involved any noticed stress in the patient that is related to whether or not the therapy is continued.	P	(Verbrugghe et al., 2014, 2016)	When there is a presumption that social support is experienced as pressure for patients, the HCP can discuss this with family and friends.
G9	The healthcare professional discusses with family and friends what it means for them to be confronted with someone suffering from cancer.	L	(Uphoff et al., 2012); QI	The care providers should gather information on the psychosocial and emotional health status of family and friends of the patients and adequately refers to specialists, depending on diagnosed problems.
G10	*New: The healthcare professional checks with the patient to what extent information may be shared with family and friends and asks for the patient's consent in this regard.	DR II		

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[a] , primary source in which was hinted to a certain key element for the first time.

[b] L,: based on literature.

[c] INT,: based on interviews.

[d] DE,: based on domain experts.

[e] DR II, retained after Delphi round two.

[f] P, key elements from practical guide based on interviews with patients as reported in Verbrugghe et al. (2014).

[g] Adaptations to the wording of the key elements after Delphi round one.

Table 2
Demographic characteristics of participating patients (n = 17), HCPs from primary care (n = 17) and HCPs in secondary care (n = 15) in both Delphi rounds.

Patients (n = 17)	N
Age	
31–40	1
41–50	4
51–60	6
61–70	5
≥71	1
Gender	
Male	8
Female	9
Marital status	
Married/civil partnership	14
Not married	3
Occupation	
Working	2
Incapacitated	10
Retired	5
Hospital of treatment	
University hospital (UH)	14
Peripheral hospital (PH)	3
Duration of treatment in months	
1–3	1
4–6	2
7–12	5
≥24	9
Primary care (n = 17)	N
Discipline	
General practitioner	4
Community pharmacist	6
Home care nurse	7
Gender	
Male	5
Female	12
Mean number of patients on OACD currently taking care for	
0	5
1–5	7
6–10	1
11–20	3
21–30	1
Secondary care (n = 17)	N
Discipline	
Oncologist/haematologist	4
Nurse/specialized and advanced practice oncology nurses	6
Hospital pharmacist	3
Student clinical pharmacy	2
Gender	
Male	4
Female	11
Patients (n = 17)	N
Years of experience in oncology	
< 1	3
6–10	3
≥11	9
Mean number of patients on OACD currently taking care for	
0	3
1–10	1
21–30	5
31–60	2
91–120	3
> 120	1

2012; van Overveld et al., 2017; Williams et al., 2018). As mentioned before, the list of KE can be used to build clinical pathways. Clinical pathways are defined as complex interventions (Vanhaecht et al., 2010) and are characterized by different interacting components (Campbell et al., 2007). The different themes of KE can be seen as the components of a complex intervention. The KE describe how to organize care (*theme A),* how to communicate with patients and family (*theme B2 and F*), what to discuss during different contacts with patients (*theme B1, C, D),* and how to provide psychosocial support *(theme E).* Theme A also entails aspects related to continuity of care; this is also one of the two additional domains of patient-centered care (i.e. access to care and continuity and transition) from the model of Picker (Gerteis et al., 1993). The KE in coordination of care and follow-up of treatment describe in which stages HCPs from primary care can be involved in an oral anticancer therapy. This is important, as the current involvement of HCPs from primary care in oncology in general and in the care for patients treated with oral anticancer drugs is limited in many settings, including Belgium (Daem et al., 2013). General practitioners (GP) are usually informed by the hospital oncology team about the start of an oral anticancer therapy, but rarely receive instructions for further follow-up. They are invited to multidisciplinary team meetings at the hospital to discuss the diagnosis and treatment procedure, but recent results show that their attendance is less than 5% (Dubois et al., 2018). This is due to the fact that these meetings take place during working hours (and technical issues with tele-participation), the fact that the discussion per patient is short compared to a long travelling time for GPs and due to GPs' perception that their input is not always valued by the oncologist (Dubois et al., 2018). The majority of GPs however, want to play a role in all stages – diagnosis, treatment and follow-up - of cancer care and in psychosocial care (Daem et al., 2013; Lawrence et al., 2016). A systematic review reported that 95% of the studied GPs prefer a more active role in cancer care and only 50% is currently involved in a shared-care model (Lawrence et al., 2016). The role of the community pharmacist (if not involved in the dispensing of OACD) is nearly non-existent. A study comparing activities from HCPs to enhance adherence to OACD between Belgian and Dutch HCPs, found that Dutch pharmacists perform considerably more activities than their Belgian colleagues (Timmers et al., 2017). This might be due to the fact that OACD in the Netherlands are dispensed by specialized pharmacies in the outpatient clinics whereas most of these drugs in Belgium are dispensed by the hospital pharmacy.

Based on our definition of consensus – i.e. 80% in all three panels – agreement was only reached for 43% of the KE. This definition is more strict than the 75% suggested by Keeney et al. (2006) and the variable definitions of consensus used (von der Gracht, 2012). In the latter paper, some Delphi-studies used 80% consensus and even 95% consensus. We decided to add KE for which in at least one panel 90%

Table 3
Detailed calculation of consensus percentages per key element and per panel of participants. Key elements were considered valid if 80% consensus was reached in all three panels or if in at least one panel 90% consensus was reached.

No.	Key element	KE retained by 80%-consensus in all panels	KE retained by 90% consensus in at least one panel	Patients (n = 17) Percentage (%) “largely”/ “in a very large extent[a]	HCPs primary care (n = 17) Percentage (%) “largely”/ “in a very large extent[a]	HCPs secondary care (n = 15) Percentage (%) “largely”/“in a very large extent[a]
THEME A. Coordination of care: framework, commitment and cooperation between different healthcare professionals						
A1	Patient contacts take place in a room with sufficient privacy (i.e. a separate interview room, no third parties present at the interview).	x		82.4	88.2	100.0
A2	Patient contacts start at the agreed time.			64.7	76.5	67.0
A3	The healthcare professionals take sufficient time for a proper interview, in which every aspect of support, that is relevant at the time, is covered.	x		100.0	100.0	87.0
A4	The healthcare professionals arrange for an adequate number of contact moments (responding to the needs of the individual patient and/or as needed for medical follow-up).	x		94.1	94.1	93.0
A5	The healthcare professionals emphasize that they are always available for questions or concerns, and provide the necessary contact details to the patient or family (including hours during which contact can be made).	x		100.0	88.2	93.0
A6	All healthcare professionals at the hospital who are involved in oral anticancer therapies are guaranteed access to relevant sources of information about it (product information, instructions on administration, expected side effects, interactions, etc.).	x		88.2	88.2	100.0
A7	Prior to contact with the patient, the healthcare professionals familiarize themselves with the prescribed anticancer medication.	x		94.1	88.2	100.0
A8	Prior to contact with the patient, the healthcare professionals at the hospital consult the multidisciplinary patient file so that they are able to make a proper assessment of the patient's situation.	x		94.1	82.4	100.0
A9	After each patient contact, the healthcare professionals at the hospital report in a shared multidisciplinary patient health record, allowing efficient exchange of information.	x		88.2	88.2	93.0
A10	The therapy plan is shared between all healthcare professionals, both in primary care and in the hospital, and each healthcare professionals responsible for reporting any changes.	x		88.2	94.1	93.0
A11	The multidisciplinary team discusses what follow-up is called for and which healthcare professional is responsible for it; this is recorded in the patient file.		x	**94.1**	70.6	87
A12	The general practitioner is involved in choices concerning the treatment, for instance via the Multidisciplinary Oncology Consultation (MOC) (This is a meeting focusing on the diagnosis and treatment of cancer patients, whereby at least three doctors with different specializations are present.).			58.8	76.5	60.0
A13	The healthcare professionals show that they collaborate with one another.			82.4	70.6	73.0
A14	At the start of the treatment, primary care healthcare professionals are informed by the hospital treatment team about the oral anticancer medication, with attention for dosage, correct use, expected side effects, interactions and medication to be avoided.		x	88.2	**94.1**	**93.0**
A15	Primary care healthcare professionals receive the necessary contact details, so that they can easily contact the hospital treatment team.	x		94.1	94.1	87.0
A16	Primary care healthcare professionals provide follow-up for the patient and are a point of contact for care issues and needs related to the oral anticancer medication.			70.6	82.4	87.0
A17	Primary care healthcare professionals are aware of the situations in which they must refer patients to the hospital treatment team.	x		100.0	100.0	93.0
A18	The healthcare professionals involve the palliative support team in the care process if necessary and when asked for by the patient.			82.4	76.5	80.0
A19	*New: All healthcare professionals who support patients with oral anticancer medication have been trained to appropriately interact with this target group, including discussing medication adherence and promoting self-management.		x	76.5	64.7	**93.0**

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Table 3 (*continued*)

No.	Key element	KE retained by 80%-consensus in all panels	KE retained by 90% consensus in at least one panel	Patients (n = 17) Percentage (%) "largely"/ "in a very large extent[a]	HCPs primary care (n = 17) Percentage (%) "largely"/ "in a very large extent[a]	HCPs secondary care (n = 15) Percentage (%) "largely"/"in a very large extent[a]
A20	The clinical pharmacist is involved in the choice and the monitoring of treatment, for instance via the 'Multidisciplinary Oncology Consultation' (MOC) (This is a meeting focusing on the diagnosis and treatment of cancer patients, whereby at least three doctors with different specializations are present.).			70.6	58.8	53.0
A21	*New: Healthcare professionals who can be contacted in emergencies at night or in the weekend, have access to the patient's file.	x		94.1	94.1	100.0
A22	The patient has easy access to his or her medical record.			76.5	64.7	60.0
THEME B1. Contact with patients: style						
B1-1	The healthcare professional takes into account a patient's coping capacity (the extent to which a patient is able process the information provided) and the patient's information needs, and adjusts the information accordingly.		x	64.7	88.2	**93.0**
B1-2	The healthcare professional takes into account the capacity of the patient to understand health information, and adjusts the information accordingly.	x		82.4	88.2	100.0
B1-3	The healthcare professional takes into account the patient's language skills, if needed s/he provides the information in the patient's mother tongue (if necessary by means of an interpreter)	x		82.4	94.1	100.0
B1-4	The healthcare professional provides the most important information first.	x		94.1	94.1	93.0
B1-5	The healthcare professional explains medical terminology to the patient.	x		82.4	94.1	100.0
B1-6	The healthcare professional poses open-ended questions (questions that invite sharing more).			70.6	76.5	87.0
B1-7	The healthcare professional leaves enough opportunity for the patient to ask questions at any time.	x		100.0	94.1	100.0
B1-8	The healthcare professional repeats the information and summarizes the most important points.	x		82.4	82.4	100.0
B1-9	The healthcare professionals do not provide contradictory information.	x		88.2	94.1	93.0
B1-10	The healthcare professional informs the patient honestly and completely, whereby no information is withheld.		x	**100.0**	58.8	87.0
B1-11	The healthcare professional checks whether the patient has understood all the information, if necessary the information is repeated and/or a second interview is planned with the patient	x		82.4	94.1	100.0
B1-12	Where possible, the healthcare professional provides information leaflets or refers to information on a website.		x	76.5	76.5	**100.0**
B1-13	*New: After a bad news consultation, the patient is given time to process this information and is to ask any questions to the healthcare professional later on.	x		82.4	94.1	100.0
THEME B2. Contact with patients: content						
B2-1	The content of the patient contact is partly defined by what is important to the patient at that moment (problems, complaints, questions, needs).	x		88.2	82.4	93.0
B2-2	Already at time of diagnosis, the healthcare professional provides sufficient information.			88.2	58.8	87.0
B2-3	The healthcare professional offers information about the disease.		x	**94.1**	70.6	**100.0**
B2-4	The healthcare professional provides information about the prognosis (prediction of the further progression of the illness).			76.5	47.0	80.0
B2-5	The healthcare professional provides information about the examinations that the patient will have to undergo, as well as the significance of their results and their impact on additional therapy.		x	**100.0**	76.5	**100.0**
B2-6	The healthcare professional provides information about what the patient can do to prevent or to alleviate certain complaints (that are related to the condition).	x		94.1	94.1	100.0
B2-7	The healthcare professional promotes self-care and provides the relevant information and support.		x	76.5	**94.1**	**100.0**
B2-8	The healthcare professional involves the patient in choices related to the treatment.		x	82.4	70.6	**100.0**

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Table 3 (*continued*)

No.	Key element	KE retained by 80%-consensus in all panels	KE retained by 90% consensus in at least one panel	Patients (n = 17) Percentage (%) "largely"/"in a very large extent[a]	HCPs primary care (n = 17) Percentage (%) "largely"/"in a very large extent[a]	HCPs secondary care (n = 15) Percentage (%) "largely"/"in a very large extent[a]
B2-9	The healthcare professional provides information about the treatment's objective.		x	**94.1**	82.4	**100.0**
B2-10	If the proposed oral medication is only available in the context of a study, the healthcare professional supports the patient in every step that needs to be taken to participate in this study (including thoroughly informing the patient about the study).	x		88.2	82.4	100.0
B2-11	The healthcare professional informs the patient about symptoms that could point to progression of the disease.			88.2	58.8	67.0
B2-12	The healthcare professional informs the patient early on about the possible (treatment) options if there is no response to the treatment or if it cannot be continued due to side effects.	x		**94.1**	64.7	87.0
B2-13	Early on, the healthcare professional discusses the options for further care planning and end-of-life care, including palliative care.			70.6	88.2	87.0
B2-14	The healthcare professional offers information about palliative care and how the palliative care team operates, in such a way that the patient understands that this does not necessarily mean 'the end'.		x	70.6	88.2	**93.0**
THEME C. Medication counselling at the start of the oral anticancer therapy: intake, adherence and adverse events						
C1	The healthcare professional gives information about the mechanism of action of the oral anticancer medication.			82.4	88.2	73.0
C2	The healthcare professional is careful about communicating that the 'best possible' medication is being started at the 'best possible' dose.			70.6	47.0	40.0
C3	The healthcare professional provides clear instructions about the use of the oral anticancer medication.	x		100.0	88.2	100.0
C4	The instructions for administering the oral anticancer medication are clearly mentioned on the label.		x	76.5	**100.0**	73.0
C5	The healthcare professional explains why correct administration of oral anticancer medication is important for the treatment results.	x		94.1	100.0	100.0
C6	Together with the patient, the healthcare professional examines how the medication can best be incorporated in the patient's day-to-day life.		x	64.7	88.2	**100.0**
C7	The healthcare professional investigates how a patient, who already has to take several medications, views the combination of his/her present treatment with the oral anticancer medication.	x		94.1	82.4	93.0
C8	The healthcare professional provides the patient with a clear medication plan, in which other medication is also mentioned (if applicable).	x		100.0	100.0	100.0
C9	The healthcare professional provides the patient with sufficient information about the medication plan so that it can be correctly and strictly followed.	x		100.0	100.0	100.0
C10	The healthcare professional informs the patient about what s/he must do if s/he has forgotten to take one or more doses.		x	**94.1**	76.5	**93.0**
C11	The healthcare professional informs the patient about what s/he must do if s/he has vomited after taking the oral anticancer medication.	x		88.2	82.4	93.0
C12	The healthcare professional provides oral and written information about the treatment's possible risks and side effects.		x	82.4	70.6	**100.0**
C13	The healthcare professional provides oral information on how the patient can deal with frequently occurring side effects.	x		94.1	88.2	93.0
C14	In order to be able to cope with less frequently occurring side effects, the healthcare professional refers to a leaflet mentioning all possible side effects, and to the possibility of telephone contact.	x		82.4	82.4	93.0
C15	The healthcare professional informs the patient about the symptoms and complaints for which s/he (urgently) has to contact the doctor or nurse.	x		100.0	100.0	100.0
C16	The healthcare professional provides the patient with information on what s/he is not allowed to eat during the treatment of his/her oral anticancer medication.	x		100.0	94.1	100.0

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C17	The healthcare professional provides information about the fact that not all medication can be taken together with the oral anticancer medication and encourages the patient to report the use of any medication (including food supplements and alternative health products) to the healthcare professionals concerned.	x		94.1	88.2	93.0
C18	The healthcare professional informs the patient about which vaccines can be administered during the treatment and some time thereafter, and which cannot be administered.		x	**94.1**	64.7	73.0
C19	The healthcare professional informs the patient about safe handling and the storage of the oral anticancer medication.			76.5	76.5	87.0
C20	The healthcare professional ensures the patient understands that the medication is only intended for him/her and may not be taken by others.			64.7	83.4	80.0
THEME D. Monitoring of treatment: usage, adherence and adverse events						
D1	During follow-up consultations, the healthcare professional's starting point is the information that was discussed at the start of the treatment and/or during earlier follow-up interviews.	x		82.4	82.4	100.0
D2	The healthcare professional inquiries into the symptoms related to the illness and the treatment.	x		88.2	94.1	93.0
D3	The healthcare professional asks the patient how s/he describes his/her quality of life and what impact the treatment has on this quality of life.		x	76.5	76.5	**100.0**
D4	The healthcare professional inquiries what the patients' impressions are of (the effects of) the medication (How does the patient perceive his/her medication and what does s/he think about it?).			76.5	64.7	80.0
D5	If relevant, the healthcare professional checks the dose of the oral anticancer medication against the present weight and the kidney and liver functions.		x	**94.1**	70.6	**100.0**
D6	The healthcare professional explains to the patient why, in certain situations, it is necessary to reduce the dose and finds out how the patient feels/thinks about this.			82.4	70.6	87.0
D7	After a dose reduction, the healthcare professional plans an evaluation moment to establish the impact on side effects and to discuss any concerns or problems.		x	**100.0**	70.6	**100.0**
D8	During the patient contact, the healthcare professional offers information about any possible change in medication.		x	82.4	70.6	**93.0**
D9	Each time the medication is changed, the healthcare professional provides the patient with a new medication plan.	x		82.4	94.1	93.0
D10	During each patient contact, the healthcare professional checks the patient's compliance with the therapy.		x	58.8	76.5	**100.0**
D11	The healthcare professional actively inquires how the patient takes his/her medication and what potentially risky situations cause him/her to forget to take it.		x	58.8	70.6	**93.0**
D12	The healthcare professional discusses with the patient how s/he sees therapy compliance and adjusts his/her support accordingly.		x	58.8	76.5	**93.0**
D13	The healthcare professional continuously encourages the patient to be adherent, with attention and respect for the patient's individuality and freedom.		x	70.6	70.6	**100.0**
D14	If the adherence of patients with oral anticancer medication is insufficient, the healthcare professional discusses the issue and works with the patient to find a solution.		x	88.2	76.5	**100.0**
D15	The healthcare professional encourages the patient to report any event of not taking the oral anticancer medication.	x		82.4	100.0	100.0
D16	If relevant, the healthcare professional inquires what the rest period (between two treatment periods) means for the patient and how difficult resuming the medication is for him/her.			76.5	70.6	87.0

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Table 3 (*continued*)

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D17	During patient contact, the healthcare professional will map and follow up the seriousness and impact on daily life of any side effects.	x		88.2	82.4	100.0
D18	The healthcare professional encourages the patient to report side effects and continues to monitor these.	x		88.2	88.2	100.0
D19	In the case of side effects, the healthcare professional attempts as far as possible to ease or tackle the symptoms.	x		100.0	88.2	100.0
D20	The healthcare professional openly communicates about side effects that are difficult to manage, both by the patient and by the healthcare professional.		x	88.2	76.5	**100.0**
D21	For each new prescription, the general practitioner checks whether the new medication may be combined with the oral anticancer medication, and if in doubt s/he contacts a healthcare professional at the hospital.	x		88.2	100.0	93.0
D22	For each new medication (both prescription and OTC), the pharmacist checks whether the new medication may be combined with the oral anticancer medication, and if in doubt s/he contacts a healthcare professional at the hospital.	x		88.2	94.1	93.0
THEME E. Psychosocial support: support of the patient and alertness to anxiety and depression						
E1	The healthcare professional pays attention to the impact of the illness and the treatment on the patient's life, roles and relationships.		x	70.6	**88.2**	**100.0**
E2	At the time of a bad news consultation with a doctor, an oncology nurse is present or available afterwards for additional emotional support.		x	70.6	**94.1**	**93.0**
E3	The healthcare professional pays attention to the degree of self-management, in particular with high-risk groups such as single and/or older patients, and offers extra support if necessary.	x		94.1	88.2	100.0
E4	The healthcare professional provides the patient with psychosocial support, even in between two consultations.			64.7	76.5	80.0
E5	The healthcare professional checks the patient's feelings and experiences to find out how the patient is coping with his/her illness and treatment, and coordinates the care accordingly.	x		82.4	88.2	93.0
E6	If necessary, the healthcare professional refers patients with psychosocial problems to specialist healthcare professionals.	x		88.2	82.4	100.0
E7	During the contact moments, the healthcare professional enquires specifically about anxiety and is alert to signals that point to this.			76.5	76.5	87.0
E8	The healthcare professional discusses the options to cope with anxiety with the patient.			76.5	70.6	80.0
E9	If the patient is finds it difficult or is unable to manage his/her anxiety, the healthcare professional will discuss with the patient the options of supplementing emotional support with medication.		x	64.7	76.5	**93.0**
E10	The healthcare professional finds out what patients look forward to and which hope and perspectives they cherish.			58.8	70.6	73.0
E11	The healthcare professional enables hope, without denying the reality of the disease and the prognosis (prediction about the further progress of the disease).			70.6	70.6	80.0
E12	During contact with patients, the healthcare professional acknowledges that waiting for examination results can be frustrating.			64.7	83.4	87.0
E13	The healthcare professional offers the patient information about patient organizations, so that s/he can get in touch with fellow sufferers to share experiences.			52.9	70.6	67.0

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E14	The healthcare professional provides the patient with information about combining his/her disease with professional activities and hobbies.			64.7	70.6	87.0
E15	The healthcare professional assists the patient with the financial aspects (insurance documents, certificates) of the treatment and if necessary refers the patient to the appropriate social services.			70.6	70.6	87.0
THEME F. Involvement of family and friends						
F1	The healthcare professional encourages the patient to take someone along to the consultation.			58.8	82.4	87.0
F2	The healthcare professional involves family and friends in the conversation.		x	76.5	52.9	**93.0**
F3	The healthcare professional offers family and friends the opportunity to ask questions.		x	82.4	76.5	**100.0**
F4	Family and friends who are closely involved, receive sufficient information about the use of the oral anticancer medication, including information about dealing with side effects.			76.5	70.6	87.0
F5	The healthcare professional encourages efforts made by the carer in the context of the patient's care.	x		82.4	88.2	87.0
F6	If desired by closely involved family and friends, the healthcare professional offers psychosocial support.			70.6	70.6	67.0
F7	The healthcare professional offers advice or helps the patient to inform their family and friends.			58.8	47.0	80.0
F8	The healthcare professional inquires with family and friends who are closely involved any noticed stress in the patient that is related to whether or not the therapy is continued.			58.8	47.0	87.0
F9	The healthcare professional discusses with family and friends what it means for them to be confronted with someone suffering from cancer.			52.9	47.0	67.0
F10	*New: The healthcare professional checks with the patient to what extent information may be shared with family and friends and asks for the patient's consent in this regard.		x	76.5	88.2	**100.0**

[a] , percentage calculated as the number of participants in a specific panel that rated the KE as “largely” or “in a very large extent.

consensus was reached. This allowed to incorporate KE that were specifically important for one panel. For the latter group of KE, it was clear that there was a disagreement in the rating of importance between the different panels. In most cases, the 90%-rule led to the inclusion of KE that were rated as important by HCPs in secondary care (which can be considered as key experts in the education and counselling of patients on OACD). However, in a few cases, the 90% rule resulted in the inclusion of KE that were specifically important for patients. Hence, patient perceptions were equally taken into account, stressing the patient-centered approach in the development and consensus-building. As aforementioned, primary care is rarely involved. Their experience with the care for these patients is therefore lacking and might be a possible explanation for these results. This limited involvement of primary care is also reflected in the overall low consensus-percentages for themes on content of patient contacts and medication counselling at the start and during follow-up in this panel. Regarding the difference in rating between patients and HCPs, prior research has pointed towards a difference in attitude between both groups. Patients rate indicators based on their perception of optimal care whereas physicians also keep practical issues in mind (Campbell et al., 2004). Patients do not seem to have the same priorities compared to HCPs. This has also been observed in other research (Verbrugghe et al., 2016). Patients seemed to pay less attention to KE concerning psychosocial support (E1, E2, E6). This might be linked to limited patient knowledge concerning elements important for an optimal care process. This is in contrast with the statement of IOM that delivering care should focus on the whole patient: care that addresses both medical and psychosocial needs (Institute of Medicine, 2008). The importance of psychosocial aspects is also reflected in the testimonial by Arora (2009).

Several limitations should be discussed. First, due to the purposive recruitment of participants, we might have received opinions from motivated HCPs only and/or from patients with an idealistic or incomplete vision on how care should be organized. As a result, the total number of validated KE remains high (n = 82). If this tool is to be used in practice to (re)define the care process in oncology centres, further prioritization must be made as aforementioned.

Due to the online surveys as part of the Delphi-approach, real-life interaction with patients and HCPs was impeded. Therefore, we missed insight in the reason and motivation for certain choices and ratings of participants and differences between the different groups. Exploration of this rationale might be of interest when further narrowing or prioritizing the list. Moreover, most patients who participated in the Delphi process were not very old neither were family and friends involved in the study. It is unclear to which extent this might have had an impact on the choices that have been made. It might well be that older patients need more psychosocial support and that involvement of family and friends is more important.

Last, for the literature search, no appraisal tool was used to assess the quality of the retrieved publications. Quality of the study was not used as a selection criterion due to the explorative character of the research topic and in order to ensure inclusion of a wide variety of papers and grey literature in order to avoid missing certain important elements. However, the search for relevant literature describing possible elements for education and counselling was performed by two independent researchers.

To our knowledge, this is the first paper that reports on the development of a set of KE in cancer care that integrates all relevant aspects in the education and counselling of patients treated with OACD. The list of KE is the first attempt to explicit which elements are part of the broad concept of patient education and counselling in oral anticancer treatments. The KE have a process-based, open formulation, which make them applicable in different contexts. We chose not to specify which type of HCP (e.g. physician, nurse, advanced practice nurse, or pharmacist) should perform the specific elements, neither to define specific tools that could be used. This allows the application of the KE in different types of hospitals and healthcare settings worldwide. Nonetheless, this set of KE is highly relevant for oncology nurses since they are -besides the physician – a key player in patient education and follow-up during oral anticancer treatments.

The usability of the list is at least threefold. First, the list can be used as an instrument to create awareness in oncology teams on the different elements that contribute to effective education and counselling of patients on OACD. This implicates that education and counselling might be performed more in-depth. Second, the list can be used by oncology teams to evaluate the level of patient education and counselling, by investigating which KE are currently implemented or performed. Lastly, the list can help to rethink and (re)design the care process for patients treated with OACD, to define tasks and responsibilities, and to prioritise actions. The open-formulated KE can then be transformed to more concrete actions within a care process, and can be complemented with information on the HCP who is responsible for that action, the tools to be used etc.

Since the KE are not formulated containing numerators and denominators, they can currently not be used as QI. It is however our aim to translate some of the items into QI (especially for KE concerning coordination of care, education at start of the therapy and follow-up) and into a checklist for observations to evaluate the level of education and counselling of patients treated with OACD.

6. Conclusion

Using information from literature, interviews with patients and HCPs from primary and secondary care and input from experts, a set of key elements was developed that was validated in a two-round Delphi approach. The final set of 82 key elements can now be used by oncology centres to evaluate, rethink and build a clinical pathway that guarantees adequate education and counselling of patients on oral anticancer drugs, and that takes into account the involvement of HCPs in clinical practice, in both primary and secondary care.

Conflicts of interest

None declared.

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