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Preparing the ground for bespoke nursing training in advanced renal cell carcinoma care (RCC4Nurses): An international prospective study

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ABSTRACT

Objectives: Nurses require specialist knowledge and skills to effectively support an increasing population of people affected by advanced renal cell cancer (aRCC). RCC4Nurses was a three-phase project that aimed to develop bespoke training in aRCC for nurses in Europe. Phase 1 examined pre-existing educational programs in kidney cancer, then developed a curriculum of core education topics in aRCC care to suit generalist and specialist nurses' education needs.

Methods: Phase 1 employed a prospective design that involved two parts. Part 1 was a scoping review of educational programs developed for multidisciplinary health professionals in kidney cancer/RCC. Findings of Part 1 formed the basis for Part 2, which was a three-round Delphi study that involved experts by personal experience or profession in aRCC, who rated the importance of a range of education topics and education methods for inclusion in the developing RCC4Nurses.

Results: The scoping review identified eight education programs via two published reports and six online resources. Existing programs had limitations in accessibility, recency and target professional groups; none of them was developed specifically for nurses. Program content was primarily focused on diagnostic, treatment and management procedures in kidney cancer. Fourteen educational topics were derived from the review and evaluated during Round 1 of the Delphi by 47 experts. By Round 3, 17 topics had iteratively reached consensus for inclusion within RCC4Nurses. Experts showed preference to problem-solving and clinical-scenario learning methods, but not reflective practice learning.

Conclusions: Given the dearth of up-to-date, evidence-based training for nurses in aRCC, we have prepared the ground to develop a bespoke training course in this area of practice.

Implications for Nursing Practice: The RCC4Nurses project will offer accessible, state-of-the-art education to registered nurses in Europe to help enhance nursing competency in aRCC and enhance the standard of care provided to people affected by aRCC.

Renal Cell Carcinoma (RCC) is the most common type of kidney cancer, although it represents just 3% of all cancers and thus is still considered rare.[1] The incidence of RCC is increasing every year, especially in developed countries within Europe.[2,3] Notably, a third of patients present with advanced disease at diagnosis, and up to 50% of early-stage cases progress to metastatic; as such, advanced RCC (aRCC) affects most people with a kidney cancer diagnosis.[4]

Living longer with an advanced disease and being on long-term treatment poses challenges that may fluctuate in intensity and may not always be evident, but require close attention and follow up by healthcare services.[5-8] Clinical guidelines recommend a combination of targeted therapies with immunotherapy.[9,10] While there is an evident effect on overall survival, there is also risk of increased toxicity related to combined therapies. Apart from side-effects such as diarrhea, hematological or liver toxicity that may require dose

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Lay Summary

What we investigated and why

Patients with advanced kidney cancer are living longer, but many still struggle with several challenges in their lives. Nurses must have good knowledge of how they can support patients and their families. This research aimed to identify what nurses should know to improve the care of patients with advanced kidney cancer.

How we did our research

The research involved two parts. The first part was a review of available training courses for health professionals who work in kidney cancer care. The second part was a consensus survey called Delphi. The Delphi asked health professionals, patients, family members, researchers, and patient advocates what they thought was important for nurses to know so that they can offer best care to people affected by advanced kidney cancer.

What we have found

The review found eight pre-existing training courses. These courses had issues with how up-to-date and accessible they were. We found no training specific to nurses. In the Delphi, the participants agreed on 17 priority topics across 4 categories: background to advanced kidney cancer; treatment of advanced kidney cancer; supportive care in kidney cancer; and practical skills for nurses.

What it means

We will use these results to prepare new training for nurses in Europe. The training is called RCC4Nurses. RCC4Nurses will support nurses to develop, refresh or update their knowledge about how to offer best care to people affected by advanced kidney cancer, which may lead to actual improvements in patient care.

reduction,[11,12] treatment combinations often result in chronic, low-grade toxicities such as fatigue or decreased appetite, which may not require treatment modification but are difficult to live with day after day in long-term administration schedules.[13] Alone or together these side effects can lead to poor treatment adherence and adversely affected health-related quality of life (HRQoL).[11,14,15] Patients with aRCC often report additional variable problems that complicate HRQoL.[5] Unmet psychological and emotional needs seem to be most prevalent in kidney cancer.[6] Previously, we reported mixed worries in a sample of 105 patients with aRCC; these included urge syndrome, worries about their condition getting worse, and worries about their family, wages and the future.[16] In the survey by Giles et al.,[17] patients with RCC reported issues with lack of understanding of the diagnosis, psychological problems, worries about not being included in clinical trials, and wishes for shared decision making. Indeed, patients with aRCC and their main careers often need to make critical decisions about treatment, supportive and palliative care, as well as develop skills and confidence to self-manage at home. This requires a supportive environment from both healthcare professionals and health care systems.

Given these potential challenges and complexities, high-quality nursing care, comprehensive monitoring, and effective multiprofessional involvement are paramount to achieve best survivorship outcomes for patients and their support network. Health professionals are required to develop strong knowledge of the range and intensity of needs of this population, as well as familiarize themselves with evidence-based ways to evaluate and manage them.[18] Within the multidisciplinary team, patients seen by specialist nurses have been reported to receive better support than those without such access.[19] Previous studies have shown how nurse-led interventions can improve the care and management of patients with cancer improving care coordination, symptom management and emotional support.[20,21] This care requires up-to-date knowledge and consolidated skills for effective nursing care. The need for continuing education in cancer care, particularly relevant to nursing practice, has been widely and globally recognised.[22-24] Regrettably, there is still a perpetuating lack of access to specialist cancer nurses in Europe[25] and a lack of specialist knowledge in kidney cancer and aRCC.[26,27] These issues combined necessitate action, that is, initiatives to provide accessible, specialist education to nurses who work in cancer care that will increase capacity, skills and competencies in aRCC care despite wide disparities in nursing education and wide diversities in health care delivery across Europe.

This study is part of the RCC4Nurses project (https://cancernurse.eu/rcc4nurses-project/). RCC4Nurses was a three-phase project the goal of which was to develop an evidence-based, free-of-charge, online educational program for nurses who work in aRCC care in Europe. Here, we present findings from Phase 1. Phase 1 aimed to:

(1) Identify and examine aspects of content and delivery mode of pre-existing educational programs in kidney cancer and/or aRCC to inform development aspects of the RCC4Nurses program, and
(2) Develop a curriculum of core education topics in aRCC to suit generalist and specialist nurses' education needs in this area of practice for inclusion in the RCC4Nurses program.

Methods

Phase 1 of RCC4Nurses employed a prospective design that involved two consecutive parts: a rapid literature review that was followed by a Delphi study.

Scoping Review

The scoping review was informed by the Joanna Briggs Institute's scoping review methodological framework[28] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).[29] The search included terms related to aRCC and education. The search terms were decided in consultation with the steering group and project team with expertise in aRCC including healthcare professionals, patients and academics. The search was conducted in MEDLINE (accessed via Ovid), PUBMED, CINAHL (accessed via EBSCO), Scopus, PsycINFO (accessed via EBSCO), Joanna Briggs Institute, Web of Science, from the date of inception to November 2022. Reports published in English, Spanish, Portuguese or Greek were selected for inclusion. Grey literature was also searched using the same search terms and inclusion criteria on Google© advanced search.

Screening

Retrieved records/reports were transferred to Mendeley reference management software and de-duplicated before they were screened based on title and abstract. Retained records/reports were accessed in full-text and further screened against our eligibility criteria.

Eligibility

Reports were eligible for inclusion if:

- They were developed for postgraduate or continuing professional development of health professionals and targeted or included content related to kidney cancer, RCC or aRCC. Although our target audience in RCC4Nurses was registered nurses, we purposely broadened our searches to identify programs targeting wider health professional audiences so that we did not miss programs addressed to multidisciplinary professionals instead of specifically to nursing.
- They were research reports that evaluated the deployment/implementation of a relevant educational program, reports that described the development of a relevant educational program, or reports offering guidance towards the development of an educational program in this area of practice.

Reports were excluded if the target was a cancer type other than kidney cancer, RCC or aRCC, or if the target was undergraduate students or individuals other than registered healthcare professionals. Non-accessible literature was excluded.

Data Extraction and Analysis

Data from the final sample of studies were extracted onto Excel spreadsheets specifically created for this review. Two authors were involved in the data extraction process. Characteristics of the identified educational programs were tabulated with specific reference to mode delivery, course content, learning methods, and evaluation of learning outcomes. Summaries of findings from the scoping review were used in subsequent expert consultation as part of the subsequent Delphi study.[30]

Delphi Study

A three-round multinational online Delphi study was conducted between December 2022 and February 2023. Delphi studies have traditionally been used in curriculum development.[31,32] The Delphi technique allows to achieve consensus within a group of expert participants, who provide independent ratings to topics or statements in consecutive rating rounds.[33] The technique allows participants to express opinions and review their answers from round to round, taking also into account other participants' answers.[34] Delphi studies often start with a first round of brainstorming, however providing experts structured statements from the existing literature is also recommended to create opportunities for generation of more ideas for consideration in a subsequent round.

Eligibility and Sampling

Participants can be considered experts due to their profession or their experience.[35] There is no definitive optimal sample size for a Delphi study, but a common suggestion is to have a minimum of representation from each group involved.[36,37] We planned to recruit a minimum of 36 experts, including patients with advanced kidney cancer, family members/caregivers, healthcare professionals working in kidney cancer care, academics/researchers in the field of kidney cancer care, and advocacy professionals. Experts were invited to participate via social media, newsletters from professionals and patient organizations, direct invitations, as well as via snowballing and word-of-mouth. We did not restrict geographical origin of expert participants in order to enhance inclusivity and breadth of opinions.

Delphi Process

An online questionnaire was developed, and subsequently set up on and distributed via Qualtrics (https://uofg.qualtrics.com). In each round, the questionnaire comprised four sections. The first section included the information sheet, privacy notice and consent. The second section collected basic participant information, such as personal or professional area of expertise, country of residence and ethnicity. The third section invited participants to rate the importance of proposed education topics related to aRCC (Table 1). In the fourth section, participants were invited to rate the importance of different learning methods. Each round also included open text questions for participants to propose additional topics or different learning methods.

Table 1
Content of the Reviewed Educational Resources Grouped Into 14 Topics and Divided Into 4 Thematic Categories

Thematic Categories/Topic
Thematic category 1: Background and significance of advanced kidney cancer
Epidemiology of advanced kidney cancer
Anatomy of advanced kidney cancer
Pathophysiology of advanced kidney cancer
Diagnosis, staging and grading of advanced kidney cancer
National/International standards of care for people with advanced kidney cancer
Thematic category 2: Treatment of advanced kidney cancer
Factors that influence treatment choices in advanced kidney cancer
Treatment options and clinical course of advanced kidney cancer
Thematic category 3: Supportive, palliative and end of life care for advanced kidney cancer
Physical and psychosocial implications of living with advanced kidney cancer
Impact of advanced kidney cancer diagnosis on the family
End of life care
Thematic category 4: Practical skills for nurses caring for people living with advanced kidney cancer
Communication with people with cancer
Emotional awareness and managing challenging situations
Information provision and education
Support services for people living with advanced kidney cancer and families
Learning resources
Group discussion
Educational resources
Reflective practice
Problem solving / problem based learning
Clinical cases

Prior to the launch of the Delphi, the first round was piloted by our steering group that comprised clinical and research experts and patient representatives. The questionnaire (originally in English) was then translated into Catalan, Croatian, Czech, Dutch, Finnish, French, German, Greek, Italian, Portuguese, Spanish, Swedish and Turkish. This was a deliberate effort to include people from different countries as language is a known barrier to participation and a driver of inequalities and skewed responses.[38,39] The questions were automatically translated within Qualtrics and checked by volunteer nurses, members of the European Oncology Nursing Society.

In the first two rounds, participants were asked to rate the importance of each topic using a nine-point Likert scale (1-3 = not to be included, 4-6 = unsure; 7-9 = should be included). Data were then exported to excel and descriptively analyzed by two authors (GK, CD). Percentage agreement across the categories "important," "unsure" and "not important" was measured. Agreement of 75% or more across two rounds was set as consensus at the beginning of the study.[40] All suggested topics and learning methods were discussed during project meetings and incorporated into the respective categories.

In rounds 2 and 3, participants were given access to results from the immediately previous round. In round 2, participants were invited to re-rate the importance of each topic/learning methods; in this round, they were also invited to rate new proposed topics. In round 3, participants were asked to indicate whether the topics and

learning methods that had not reached consensus in the two previous rounds were considered important or not by responding to a final binary question: "Yes, include" or "No, reject". Each round remained open for 2 weeks. Participants who missed Round 2 (without expressly withdrawing from the study) were allowed to return and take part in Round 3. Ethical approval was obtained from the College of Medical, Veterinary & Life Sciences Ethics Committee, University of Glasgow (ref. no 200220053).

Results

Scoping Review

From 1960 records identified via database search, only two published articles met our eligibility criteria.[41,42] Twenty-eight educational programs were also identified from other sources (Fig. 1). However, only six programs had content related to kidney cancer. In total, eight educational programs were included for review.

Overview of the identified programs:

The two published articles evaluated the effectiveness of educational programs for physicians, using pre- and post-training surveys (Table 2). Lavallée et al.[41] developed educational content via a needs assessment survey which was developed by a multidisciplinary group. The content of the program was generic on kidney cancer including diagnostic, treatment and management procedures. Separately, Cohen et al.[42] based development of educational content on anecdotal experiences, specifically focusing on communication in advanced kidney disease, which did not include cancer-only cases but had cases on communication of bad news due to disease progression. Both studies were conducted in English-speaking countries. Lavallée et al. also provided a French version for hospitals in French-speaking parts of Canada.

Among the remaining six training courses, five were found freely available on the Internet, whereas the last one was available online but only members of Kidney Cancer UK, and we were given access to an outdated version of it.[43-48] The training courses varied in length from 15 minutes (the shortest) to 8 hours (the longest) (Table 2). Topics and learning outcomes also varied widely. For instance, the COR2ED[43,44] podcasts or the Medscape[45] course specifically focused on treatments, while the Kidney Cancer UK course,[46] the National Cancer Institute (NIH) course[47] and the European Association or Urology (EAU) course[48] explained kidney cancer in a more comprehensive way. Except for the COR2ED podcasts that were made specific for physicians and for nurses, the rest of courses targeted healthcare professionals without specifying the discipline. None of these courses had any evaluation published. All six training courses were developed in English only.

Topics

Most of the content was developed for kidney cancer (n = 5) except the study by Cohen[42] that included kidney disease in general but included kidney cancer, including RCC. The EAU course[48] was on RCC both early stage and advanced. The Medscape[45] course and the COR2ED[43] podcasts were specific to aRCC. Content was grouped into 14 topics divided into 4 thematic categories (background to aRCC, treatment of aRCC, supportive oncology in RCC, practical skills for nurses).

Learning Methods

All programs and courses included educational resources as the main learning method. The two published studies referred to face to face learning, while all six training courses were offered online. The face-to-face courses used clinical cases, some with simulated

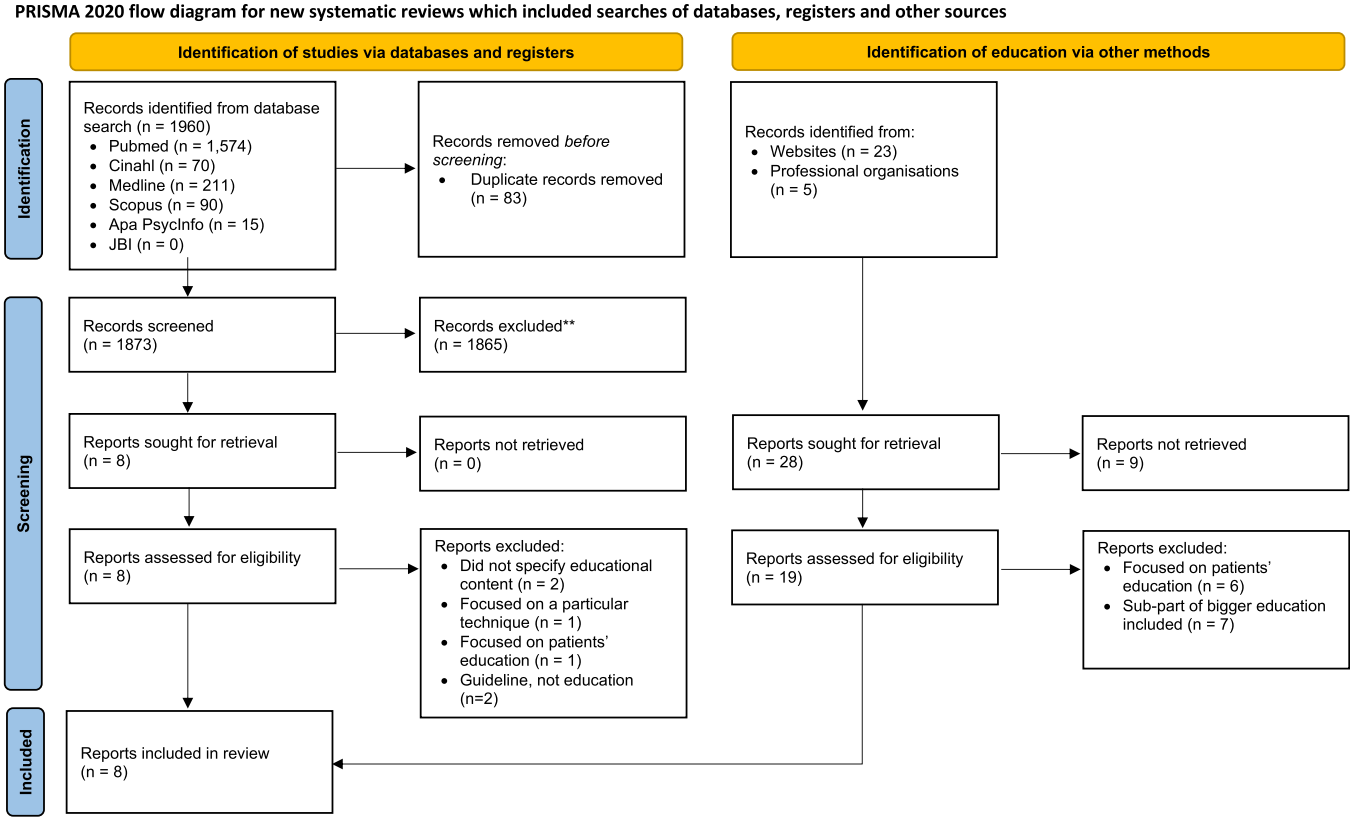

Fig 1. PRISMA diagram of the record screening/selection process

Table 2
Characteristics of the Reviewed Educational Studies and Educational Program for Healthcare Professionals in Kidney Cancer

Title of program	Program characteristics	Target program topics / competencies
COR2ED [43,44]	*Target Audience: 2 programmes: one for nurses and one for physicians* *Teaching methods: Podcasts (one for nurses, one for physicians)* *Length: 35 mins (nurses), 15 mins (physicians)* *URL: https://cor2ed.com/gu-connect/programmes/the-role-vegfr-tkis-in-the-treatment-of-advanced-rcc-alone-or-in-combination/& https://cor2ed.com/gu-nurses-connect/programmes/setting-up-for-treatment-success-podcast-on-management-of-patients-receiving-vegfr-tki-treatment-for-select-solid-tumours/*	*Treatment* *Treatment side-effects*
EAU [48]	*Target Audience: Healthcare professionals* *Teaching methods: Reading material through the EAU guidelines* *Length: 1 day* *URL: https://uroweb.org/education-events/eau-guidelines-on-renal-cell-carcinoma*	*Epidemiology aetiology and pathology* *Staging and classification systems* *Diagnostic evaluation* *Prognostic factors* *Disease management* *Follow up*
NIH [47]	*Target Audience: Healthcare professionals* *Teaching methods: Reading material.* *Length: Not specified* *URL: https://www.cancer.gov/types/kidney/hp*	*Incidence* *Mortality* *Treatments* *Follow up*
Medscape [45]	*Target Audience: Healthcare professionals* *Teaching methods: Reading material* *Length: Not specified* *URL: https://www.medscape.org/viewarticle/911534*	*IO therapy and combination therapy*
Kidney Cancer UK course [46]	*Target Audience: Healthcare professionals* *Teaching methods: Reading material, clinical cases, problem solving* *Length: Not specified* *URL: Offline, originally from https://healthpro.kcuk.org.uk/*	*Anatomy, pathophysiology, aetiology & epidemiology* *Diagnosing and staging* *Renal cancer surgery* *Drug treatment for renal cancer* *Palliative care of renal cancer patients* *Information and support for those affected by renal cancer* *Case studies* *The future of renal cancer*
Lavallée et al. (2019), Canada [41]	*Target Audience: Clinicians (uro-oncologist and medical oncologist)* *Goal: To improve clinician knowledge and patient care.* *Curriculum: Needs assessment survey to decide topics.* *Developed by: Multidisciplinary group of urologists, medical oncologists, nurses, and research assistants.* *Teaching methods: Case-based scenarios.* *Length: not specified*	*Prognostic factors for advanced disease* *Indications for surgery for advanced disease* *Indications for hereditary screening.* *Management of systemic therapy and side effects.* *Management of patients with small renal masses.*
Cohen et al. (2016), USA [42]	*Target Audience: Clinicians (nephrologist fellows)* *Goal: To enhance communication in difficult conversations throughout the trajectory of advanced kidney disease.* *Curriculum: Not defined.* *Developed by: Faculty members with knowledge in advanced communication.* *Teaching methods: Didactics, discussion, and reflective practice with simulated patients* *Length: One day*	*Delivering bad news* *Acknowledging emotion* *Discussing care goals in dialysis decision making when prognosis is uncertain* *Addressing dialysis therapy withdrawal and end of life.*

EAU: European Association or Urology, NIH: National Cancer Institute.

patients, reflective practice and group discussions. The Kidney Cancer UK course[46] also included case studies. The rest of training courses only had written content from educational resources mainly passive learning with reading material[47,48] and or audio.[43,44] The learning methods were grouped into 5 categories, that is, group discussion, educational resources, reflective practice, problem solving/problem based learning and clinical cases.

Evaluation of Participants' Learning

The studies by Lavallée et al. and Cohen et al.[41,42] used pre- and post-training questionnaires to measure the effectiveness of the programs. Both studies reported improvement in participants' knowledge immediately post-education and 3 months after. The Medscape[45] course also included pre- and post-training questionnaires to evaluate learning. The Kidney Cancer UK course[46] had questionnaires and case studies on each of the modules to assess the learning outcomes of each module. The rest of courses had no formal evaluation. The learning topics and learning methods resulted from the review were presented consulted and discussed among the project team and with the steering group prior to the Delphi study.

Delphi Study

There were 47 respondents in Round 1, 20 to Round 2, and 33 to Round 3. Across the three rounds, most participants were patients with aRCC (51%, 50% and 51.5%, respectively) followed by health professionals (30%, 35% and 33.3%, respectively). There was representation of all 5 groups in all rounds except for Round 2, whereby no family members or researchers took part. The typical patient and family member was in their 50s. Health professionals and advocacy professionals typically had close to 19 years of working experience. Participants were primarily based in Europe (Table 3).

A summary of Delphi results for Rounds 1-3 is presented in Table 4. In Round 1, 12 of the 14 educational topics (all but epidemiology of advanced kidney cancer and pathophysiology of advanced kidney cancer) and two of the educational methods (educational resources and problem-based learning) reached the 75% cut point for consensus. There were 23 comments from which 3 new topics were

Table 3
Demographic Characteristics of the Delphi Expert Participants

	Round 1 ($n = 47$)		Round 2 ($n = 20$)		Round 3 ($n = 33$)	
Personal/Professional background	n	%	n	%	N	%
A health professional with experience looking after people living with advanced kidney cancer	14	30%	7	35%	11	33.3%
A person who lives with advanced kidney cancer	24	51%	10	50%	17	51.5%
A researcher with experience in the field of advanced kidney cancer	2	4.2%	0	0%	2	6.1%
A family member or caregivers of a person who lives with advanced kidney cancer	5	10.6%	0	0%	1	3%
An advocacy professional with experience in advanced kidney cancer	2	4.2%	3	15%	2	6.1%
Country of residence/practice:	**n**	**%**	**n**	**%**	**n**	**%**
United Kingdom of Great Britain and Northern Ireland	30	61%	11	58%	14	42%
Canada	1	2%	2	11%	2	6%
Denmark	2	4%	0	0%	0	0%
Estonia	1	2%	0	0%	0	0%
Ireland	4	8%	1	5%	1	3%
Netherlands	1	2%	1	5%	0	0%
Palestine	1	2%	0	0%	0	0%
Spain	5	10%	2	11%	3	9%
South Africa	1	2%	0	0%	2	6%
Switzerland	1	2%	1	5%	0	0%
USA	1	2%	0	0%	2	6%
France	1	2%	2	11%	2	6%
Belgium	0	0%	0	0%	1	3%
India	0	0%	0	0%	2	6%
Italy	0	0%	0	0%	1	3%
Sverige	0	0%	0	0%	1	3%
Turkey	0	0%	0	0%	1	3%
Tanzania	0	0%	0	0%	1	3%
Gender	**n**	**%**	**n**	**%**	**n**	**%**
Male	19	40%	7	35%	16	48%
Female	27	57%	12	60%	17	52%
Prefer not to say	1	2%	1	5%	0	0%

created for consideration in Round 2 (supporting self-management skills of people living with advanced kidney cancer; palliative care of renal cancer patients: specialist and non-specialist palliative care; oncological emergencies in advanced kidney cancer). One of the learning resources was split into group discussion and clinical cases also following participants' suggestions.

In Round 2, all but one topic reached consensus (epidemiology of advanced kidney cancer; 74% agreement). Also, reflective practice did not reach consensus. In Round 3, only those topics and learning methods that did not reach consensus in the previous two rounds were consulted with the experts. In Round 3, all educational topics reached consensus, but reflective practice did not and was thus eliminated. All the topics that reached consensus are presented on Figure 2

In response to an invitation for comments and suggestions across all rounds, three patients with aRCC commented they did not feel comfortable deciding how nurses should learn. Another patient commented: "*Caring and compassion are key. I need to feel like a person not a number. So, see me each visit. Learn about me and treat me like I matter*". There were also comments from patients highlighting how promotion of physical activity and psychological support for anxiety or how to manage life expectancy was important for them.

Discussion

We examined pre-existing educational programs in kidney cancer, then developed a curriculum of core education topics in aRCC care to suit generalist and specialist nurses' education needs. Our scoping review revealed a lack of educational resources developed specifically for nurses in this area, educational programs in kidney cancer/RCC that were limited in scope or outdated, no clear evidence of how existing educational programs had been developed, lack of evidence of patient and public involvement in the development or delivery of these programs, and scarcely implemented program evaluation. We thus identified a gap to be filled by a comprehensive nursing educational program in aRCC care. By involving a wide panel of relevant experts in our Delphi study, we also identified with confidence that priority educational topics to enhance nurses' competencies in aRCC care should provide a comprehensive background to aRCC, discuss treatment options in aRCC, consolidate knowledge pertinent to supportive oncology, and focus on the practical skills that generalist and specialist nurses require irrespective of level of practice or work experience in kidney cancer.

Patients with aRCC experience changes in life that affect HRQoL and cause psychological distress.[5] Dealing with the side-effects of treatment and with worries about prognosis and concerns about their family are especially important.[7,16] While in the literature emotional concerns are the most commonly reported needs in this population,[6] traditionally, clinical trials that involved patient self-reports have put a predominant focus on physical problems.[8] People affected by cancer require an abundance of well-coordinated resources to help them navigate the cancer pathway. Importantly, they need knowledgeable and empathetic health professionals to guide and inform them. If health professionals are focusing mainly on the physical symptoms, a large side of life with aRCC will be missed. Provision of holistic assessments, high-quality information and personalized support are key parameters to improve a patient's experience. In aRCC, nurses need to be well-informed of the pathophysiology and demography of aRCC, what specific problems patients and families face, what resources are available locally and online, and how to appropriately communicate to assess, refer and manage problems as they arise.[49] While some countries have developed specialist nursing roles for kidney cancer, most people affected by aRCC rely on generalist nurses who are nevertheless still required to apply specialist knowledge and skills to provide effective, tailored care.

Patients with cancer often rely on available community resources, such as patient support groups. People can find great support and

TABLE 4
Delphi Results From Rounds 1-3 Organized in % Agreement to the Respective Statement and Response Option

Module / Topic	Round 1 (n = 47)			Round 2 (n = 20)			Round 3 (n = 33)	
	Should not be included %	Unsure %	Should be included %	Should not be included %	Unsure %	Should be included %	Reject %	Include %
Thematic category 1: Background and significance of advanced kidney cancer								
Epidemiology of advanced kidney cancer	2%	31%	67%	5%	21%	74%	11%	89%
Anatomy of Advanced kidney cancer	4%	19%	76%	0%	16%	84%	-	-
Pathophysiology of advanced kidney cancer	2%	30%	68%	0%	15%	85%	8%	92%
Diagnosis, staging and grading of advanced kidney cancer	0%	7%	93%	0%	5%	95%	-	-
National/International standards of care for people with advanced kidney cancer	2%	9%	88%	0%	5%	95%	-	-
Thematic category 2: Treatment of advanced kidney cancer								
Factors that influence treatment choices in advanced kidney cancer	2%	2%	95%	0%	0%	100%	-	-
Treatment options and clinical course of advanced kidney cancer	0%	2%	98%	0%	5%	94%	-	-
Oncological emergencies in advanced kidney cancer	-	-	-	0%	10%	90%	3%	97%
Thematic category 3: Supportive, palliative and end of life care for advanced kidney cancer								
Physical and psychosocial implications of living with advanced kidney cancer	0%	7%	93%	0%	0%	100%	-	-
Impact of advanced kidney cancer diagnosis on the family	0%	11%	89%	0%	6%	95%	-	-
End of life care	2%	16%	82%	0%	6%	94%	-	-
Palliative Care of Renal Cancer Patients: Specialist and non-specialist palliative care	-	-	-	6%	17%	78%	3%	97%
Supporting self-management skills of people living with advanced kidney cancer	-	-	-	0%	0%	100%	0%	100%
Thematic category 4: Practical skills for nurses caring for people living with advanced kidney cancer								
Communication with people with cancer	0%	4%	95%	0%	6%	94%	-	-
Emotional awareness and managing challenging situations	0%	2%	98%	0%	6%	95%	-	-
Information provision and education	0%	2%	98%	0%	0%	100%	-	-
Support services for people living with advanced kidney cancer and families	0%	11%	89%	0%	6%	94%	-	-
Learning resources								
Group discussion	2%	29%	70%	0%	29%	72%	17%	83%
Educational resources	2%	21%	77%	0%	6%	95%	-	-
Reflective practice	5%	25%	70%	0%	33%	67%	29%	71%
Problem solving / problem based learning clinical cases	0%	22%	78%	0%	17%	83%	-	-
	2%	29%	70%	0%	0%	100%	0%	100%

comfort in speaking to peers with similar struggles often in the presence of coordinating health provider.[50,51] Studies have demonstrated the positive psychosocial effects on those who attend professionally led support groups.[52] In kidney cancer, however, support groups outside the United Kingdom are still largely underdeveloped. In addition, our scoping review found that most educational courses were focused on diagnosis and treatment, and not on how to provide psychosocial support. The study by Cohen[42] and Kidney Cancer UK course[46] were the only ones that included content on communication and only the Kidney Cancer UK course[46] had content on information and support for people affected by kidney cancer. It must be noted how the topics around epidemiology and pathophysiology were included in all the courses we analyzed in the scoping review; however, they were the only ones that required all three Delphi rounds to reach consensus. While health professionals were rating epidemiology and pathophysiology as very important in all Delphi rounds, some patients and family members were ambivalent about their potential value in nurses' education in aRCC care, possibly because of uncertainty about how this knowledge could directly impact nursing care and patient benefit.

In our scoping review, four programs formally evaluated learning outcomes of their participants.[41,42,45,46] When developing educational programs for health providers it is paramount that evaluation abides by structured methods such as the Moore or Kirkpatrick frameworks.[53,54] Such frameworks consider different levels of evaluation that move beyond basic satisfaction or immediate post-course impact on learning to consider changes at higher level that focus on health providers' clinical behavior and practice that may be bring about direct impact on patient care. Measuring impact on these higher levels is challenging and complex, which explains why frequently evaluation of educational programs is limited to evaluation outcomes at lower levels that are more straightforward to measure.[55] Nevertheless, it is essential to consider best evaluation methods according to the educational objectives of a given educational program.

Although treatment guidelines in aRCC are generally similar across Europe, there are differences on how services are structured and provided to patients and families, including access to specialist nursing care.[56] Nurses in cancer care, because of their unique position as the main point of contact for cancer patients, are the main information providers and in an ideal position to identify, assess and coordinate support for unmet patient needs in aRCC.[23] Nurses in cancer care are also key informants and interpreters of information to help patients and their support network navigate the healthcare system,

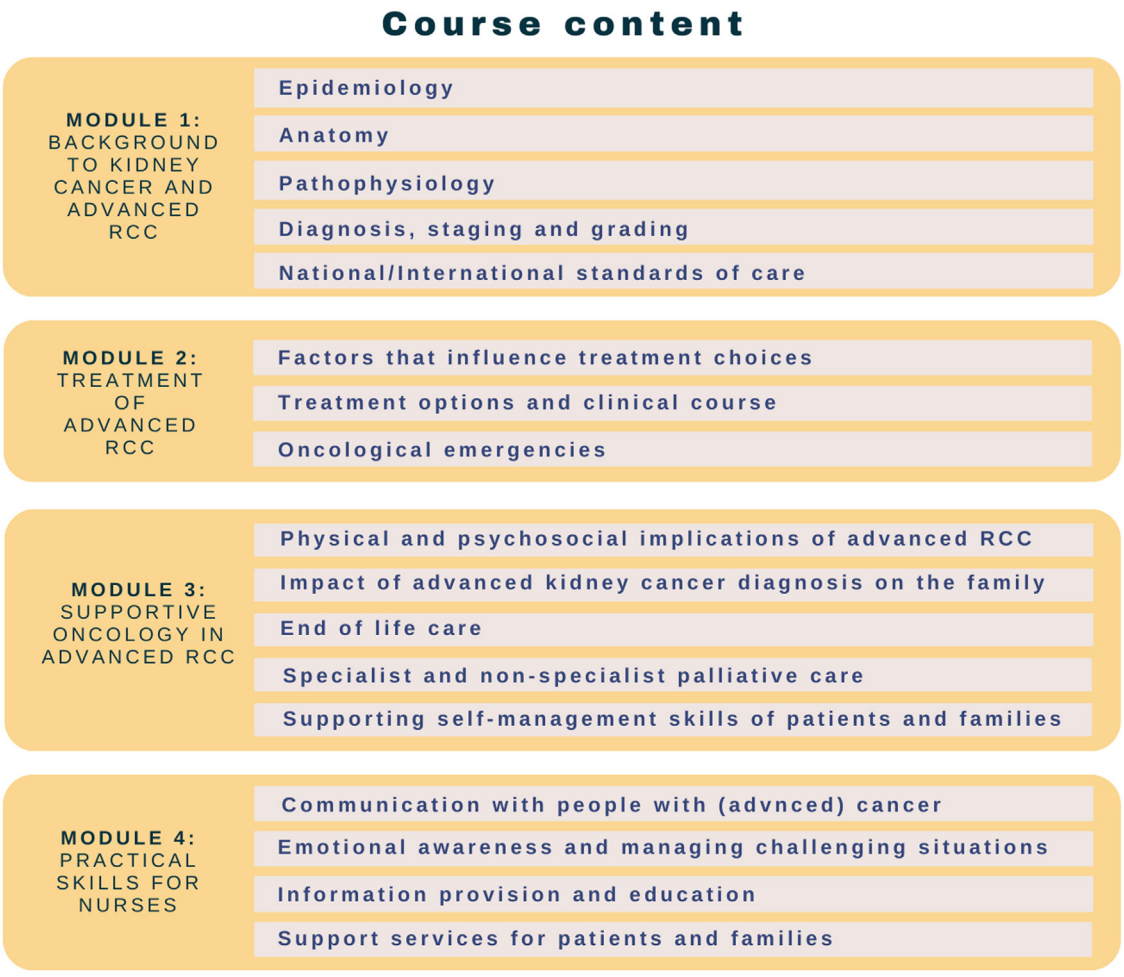

Fig 2. Final topics agreed at the end of the Delphi study for inclusion in RCC4Nurses.

not only by recommending resources but also implementing and/or coordinating interventions.[27,57] That being said, multidisciplinary effort is paramount to provide best supportive care to people with aRCC, and highly trained and skilled nurses in aRCC care can make a real difference in how multidisciplinary effort is operationalized and applied in practice. Lack of training in aRCC and the lack of nurses with specialist knowledge/skills in kidney cancer care providing a disservice that can only adversely impact the overall experience of these patients and their support network.[58]

Lastly, not all teaching methods reached consensus in our Delphi, particularly reflective practice. A similar finding was reported in a study building consensus for nursing education in advanced breast cancer,[32] where reflective practice also did also not reach consensus. This could be the result of two factors: one is that reflective practice is not common in clinical nursing practice in all countries and as such was discounted on the grounds of unfamiliarity;[59] the other is that reflective practice is commonly associated with and enriched by a discussion with a colleague, teacher or supervisor.[60] Such functionality could not be accommodated by online courses such as RCC4Nurses that was not planned to cater for synchronous or asynchronous interaction with a mentor.

Strengths and Limitations

Our scoping review was purposely broad to promote inclusivity and reduce the chance to miss relevant educational program. In the Delphi, we were as inclusive as possible regarding the proposed topics, and flexible to allow experts to suggest new topics that we incorporated for consultation. To reduce the attrition rates the study was open for new participants in the three rounds. We also allowed participants who missed round 2, to come back and participate in round 3. Our Delphi experts formed a sample of geographic diversity and varied clinical experience and expertise that strengthen our findings.

While the Delphi was translated into fourteen languages to prevent a possible language barrier and foster inclusivity and diversity, we should note that the largest part of our experts in every round (almost 50%) came from English speaking countries, particularly the United Kingdom, which may have skewed our results. Considering how different nursing practice across Europe is, having many experts from the same country may not allow for a clear view of needs in nursing education that apply more widely to all of Europe.[25,26] It is also important to note that representation of family members in the Delphi was rather smaller, reaching only 10.6% at maximum. Other limitations of the study come from the online delivery of this Delphi, which might have excluded potential participants due to issues of digital literacy.

Conclusions

A European online training program has the potential to encourage harmonization of awareness of patient need and better care for all with aRCC, irrespective of country-specific disparities in training and diversities in clinical practice.[24,25] Having identified core educational areas, the results of this study have served to build a bespoke educational program for nurses in aRCC. Improving nurses' access to

evidence-based, up-to-date education that is based on clear understanding of the needs of people affected by aRCC could help towards direct improvements in patient care.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Daniel Kelly was a Guest Editor for the "Kidney Cancer" Special Issue of Seminars in Oncology Nursing. As an author of this article, he did not participate in any editorial process or decision-making, which was handled by another editor.

Grigorios Kotronoulas is the Editor in Chief of Seminars in Oncology Nursing. As an author of this article, he did not participate in any editorial process or decision-making, which was handled by another editor.

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CRediT authorship contribution statement

Celia Diez De Los Rios de la Serna: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Visualization. **Constantina Papadopoulou:** Writing – review & editing, Validation, Methodology, Data curation, Conceptualization. **Amanda Drury:** Writing – review & editing, Validation, Methodology, Data curation, Conceptualization. **Wendy Oldenmenger:** Writing – review & editing, Validation, Methodology, Data curation, Conceptualization. **Theresa Wiseman:** Writing – review & editing, Validation, Methodology, Data curation, Conceptualization. **Daniel Kelly:** Writing – review & editing, Validation, Methodology, Data curation, Conceptualization. **Grigorios Kotronoulas:** Writing – review & editing, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

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