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Identifying the unmet supportive care needs of people affected by kidney cancer: a systematic review.

O'DEA, A., GEDYE, C., JAGO, B. and PATERSON, C.

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Title: Identifying the unmet supportive care needs of people affected by kidney cancer: A systematic review

Authors: Amy O'Dea (BTh)[a,c], Craig Gedye (BScHons MBChB FRACP PhD)[f,g,h], Belinda Jago (BBusAcc, Consumer), Catherine Paterson (PhD, BA, MSc, PgCert LTA, FHEA, RAN)[a,b,c,d,e]

[a] Faculty of Health, University of Canberra, Bruce ACT, Australia

[b] Prehabilitation, Activity, Cancer, Exercise and Survivorship (PACES) Research Group, University of Canberra, Bruce ACT, Australia

[c] School of Nursing, Midwifery and Public Health, University of Canberra, Bruce ACT, Australia

[d] Canberra Health Services & ACT Health, SYNERGY Nursing & Midwifery Research Centre, ACT Health Directorate Level 3, Building 6, Canberra Hospital, Australia

[e] Robert Gordon University, Aberdeen, Scotland, UK

[f] Senior Staff Specialist, Calvary Mater Newcastle

[g] Director, HMRI Clinical Trials

[h] Conjoint Associate Professor, School of Medicine and Public Health, University of Newcastle

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Corresponding Author:

Professor Catherine Paterson

Clinical Chair in Nursing

School of Nursing, Midwifery and Public Health, University of Canberra, Bruce ACT, Australia

Email: Catherine.paterson@canberra.edu.au

Telephone: +61 (0)2 6206 8419

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Abstract:

Purpose: To synthesise existing evidence on the unmet supportive care needs of people affected by kidney cancer, across the cancer care continuum.

Methods: A systematic review was conducted according to the PRISMA Statement Guidelines. Electronic databases (CINAHL, MEDLINE and PsychINFO) were searched using key search terms. Articles were assessed according to pre-specified eligibility criteria. Data extraction and quality appraisal was conducted. The findings were integrated in a narrative synthesis.

Results: 1063 publications were screened, and 18 publications met the inclusion criteria. The following domains of unmet needs in order of frequency included: psychological/emotional needs (17/18: 94%), physical needs (10/18: 56%), social needs (4/18: 22%), interpersonal/intimacy needs (4/18: 22%), patient-clinician communication needs (3/18: 17%), family related needs (3/18: 17%), health system/information needs (3/18: 17%), spiritual needs (3/18: 17%), daily living needs (2/18: 11%), practical needs (1/18: 6%) and cognitive needs (1/18: 6%).

Conclusions: There was a wide range of unmet supportive care needs experienced by people diagnosed with kidney cancer. A prominent focus was on psychological and physical needs. Further research is needed to understand how clinical (stage/treatment) and demographic (age/socio-economic/ethnicity) variables may moderate or mediate the relationship with unmet needs over time. With many unmet needs identified, this review provides a starting place to inform future work to address the complex unmet supportive care needs of people affected by kidney cancer.

Implications for Cancer Survivors: Individuals living with kidney cancer have many unmet supportive care needs, and future research is needed to learn about what are the most pressing needs and how to best address these concerns to ensure holistic person-centred care is delivered.

Key words: Supportive care needs, Kidney cancer, Quality of life, systematic review

Introduction

Kidney cancer is the 14th most common newly diagnosed cancer and represents a significant growing global health burden [1]. The incidence of kidney cancer has trended upwards over recent decades [2]. In 1990, there were approximately 207 000 new diagnoses; in 2020, it was estimated that there were over 400 000 new kidney cancers diagnosed, representing approximately a 50% increase over the past 30 years [1]. Factors reported as potentially contributing to this increase include lifestyle changes, increased tumour detection, reporting and exposure to risk factors [2].

Only 10% of kidney cancer diagnoses now occur with the 'classic triad' of haematuria, flank pain and a palpable mass [3], and many diagnoses occur early as a 'small renal mass' through incidental imaging. Clinical management varies by stage, grade and comorbidities [4, 5]; broadly, management of localized kidney cancer may include active surveillance, partial or radical nephrectomy, stereotactic radiation and thermal ablation therapies [4-8]. Localised kidney cancers, such as small renal masses creates management dilemmas for patients, of which many are elderly with other existing comorbid conditions [9, 10]. For people with locally advanced unresectable/metastatic kidney cancer the treatment options most often includes molecularly targeted cancer therapies and immunotherapy [4, 5]. The trend towards an increased incidence of kidney cancer accompanied with the complexities of associated treatments means that many more people will require supportive care [2].

Supportive care is broadly defined as the necessary cancer services for those affected by cancer to meet their person-centred physical, emotional, social, psychosocial, informational, spiritual and practical needs during diagnosis, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement [11]. There is emerging data about specific unmet supportive care needs of people affected by kidney cancer [12-14], but historically, studies have largely focused on disease specific outcomes, such as survival rates [15]. However, there is indication that unmet needs for people with kidney cancer can include high levels of distress [14], depressive symptoms [12], pain, fatigue, changes in mobility and social functioning [13], with decreased sexual function [12]. Evidence has underscored that people affected by cancer who have experienced unmet supportive care needs can negatively impact their physical and psychological wellbeing, and overall recovery and rehabilitation [12-14].

Given the reported experiences of unmet supportive care needs of people affected by kidney cancer [12-14] it is important to take stock of the existing evidence to identify what are the domains of unmet needs, and what is the most frequently experienced unmet supportive care need among people affected by kidney cancer to inform holistic person-centred evidence-based guidelines, future directions for research and practice. Therefore, this systematic review will address the following clinically focussed research questions:

1) What are the unmet supportive care needs of people affected by kidney cancer?
2) What is the most frequently reported individual domain of unmet supportive care needs?

Methods

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRIMSA) guidelines published in 2009 [16], see **Supplementary Table 1** for completed checklist.

Search strategy

The following electronic databases were searched: MEDLINE, CINAHL and PsychINFO. The search architecture used a wide range of keywords and free text items (such as kidney cancer, renal cancer kidney neoplasm, care needs, supportive care needs, needs assessment, and caregiver needs) to increase the sensitivity and inclusiveness of the searches (see **Supplementary Table 2** for an example the electronic database search). Inclusion and exclusion criteria were applied to all records identified. The electronic searches began on 20th November 2020 and concluded on 26th November 2020. All records were managed using the software package Endnote X8 and uploaded to Covidence systematic review software. Duplication of records were removed. A pre-selection eligibility criteria was applied to all records.

Pre-selection Eligibility Criteria

Types of studies

- Qualitative and quantitative methods irrespective of research design.
- Commentaries, editorials, and studies where unmet supportive care needs were not reported were excluded.
- Studies published in peer-reviewed journals between 2010-2020.

Types of participants

- Participants (≥18 years of age) with a confirmed histological diagnosis of kidney cancer and their partners.
- All stages of disease and treatment modalities were included.
- Studies conducted with patients with mixed cancer groups, except when a separate sub-group analyses of only kidney cancer participants were reported were included.

Types of outcomes measures

- The primary outcome of this review was non-oncological outcomes related to: unmet supportive care needs (e.g. the Supportive Care Needs Survey [17] and qualitative experiences, informed by the definition of supportive care [11])

Study selection and data extraction

The publications (titles and abstracts) were double screened independently by two authors to promote consistency and reliability in the application of the eligibility criteria. All articles which met the inclusion criteria were retrieved in full-text. Full-text articles were double screened with any disagreements resolved by discussion. One author extracted data from the final sample of studies and these were all quality checked by a second author using pre-determined data extraction tables.

Data extraction

The extracted data included 'characteristics of included studies' (study design; countries and institutions where the data were collected; participant demographic and clinical characteristics, unmet supportive care needs coded into domains; the numbers of participants who were included in the study; losses and exclusions of participants, with reasons). Specifically, data in relation to unmet supportive care needs was informed by existing literature and clinical expertise, see **Table 1**. Individual unmet supportive care needs were classified into eleven domains: physical, psychological/emotional, cognitive, patient-clinician communication, health system/information, spiritual, daily living, interpersonal/intimacy, practical, family related and social needs [18].

Quality appraisal

The quality appraisal of all included studies was conducted by utilising the Mixed Methods Appraisal Tool (MMAT) [19]. The MMAT enabled quality appraisal of: qualitative research, randomized controlled trials, quantitative descriptive studies, and mixed methods studies [19]. There are seven questions for each category of study design which were ranked as “Yes” (green), “Unclear” (yellow) or “No” (red). The quality appraisal enabled the research team to identify limitations and potential bias within each of the individual studies. No study was excluded based upon individual methodological quality appraisal scores to enable an understanding of the current state of the evidence base.

Data synthesis

This review completed tabulation of primary research studies and used of narrative synthesis to generate findings. The data synthesis process followed the integrated review methodology proposed by Whittemore and Knafl [20]. Specifically, this involved data reduction (subgroup classification by domain of unmet need, with results tabulated), data comparison (identifying patterns and themes through clustering and counting, and making contrasts and comparisons) and conclusion drawing and verification (synthesis of subgroup analysis to inform a comprehensive understanding of the topic, verified with the primary source data for accuracy). Data synthesis was reviewed by a multidisciplinary research team, including clinicians and a patient advocate.

Results

1063 publications were screened (of which four were identified from backward chain linking and 20 from grey literature), 44 articles were assessed in full and 18 publications met the inclusion/exclusion criteria (see **Figure 1**, PRISMA). The publications were conducted in the following countries: n8 United States of America, n3 Canada, n2 Germany, n1 Australia, n1 Korea, n1 Norway, n1 Denmark and n1 Italy (see **Table 2** for an overview of included studies). Noteworthy, three of the publications reported data from the same study [21-23]. Two publications further reported on the same study [24, 25]. Therefore, a total of 15 studies were included in this review which indicates that this is an emerging area. Two studies included information from mixed cancer study populations but reported the kidney cancer participants unmet needs separately [26, 27]. Across the 15 included studies, the study size ranged from 28 to 1990 participants with kidney cancer. There was a total of 4464 participants with kidney cancer included in this review.

Six publications included participants with localised renal cell carcinoma [24, 27-31], one publication included participants with only small renal masses [25], six publications included participants with either localised or metastatic kidney cancer [15, 21-23, 32, 33], two publications included patients with only metastatic kidney cancer [34, 35], two publications did not report the stage of kidney cancer [26, 36], and one publication retrospectively reviewed a localised kidney cancer cohort, that by the time of publication some participants had unfortunately progressed to metastatic disease [37]. In total, the publications included two mixed studies, 15 quantitative studies and one qualitative study.

Quality appraisal

The results of the methodological quality appraisal of the included articles are presented in **Table 3**. There were a number of limitations identified across the included studies, which included: high risks of non-response bias, either due to low response numbers or not reporting the reasons for non-participation which limits the generalisability of the results of these studies [15, 23-26, 29-34].

The level of evidence as reported by the studies included in this review were classified as randomised control trial (B1), reported over three publications [20-22] and the remainder of the studies were classified at level B3 (according to the e levels of evidence by the Department of Health in the National Service Framework [see **Supplementary Table 3**] [38]).

Evidence of unmet supportive care needs by domain

There were several unmet care need domains identified among people affected by kidney cancer (see **Supplementary Table 4**).

Psychological/emotional needs

Psychological or emotional needs were the most commonly reported domain of need. Unmet psychological and emotional needs included anxiety [15, 21, 22, 28, 30, 33, 34, 37], fear of recurrence [28, 30], fear of medical procedures [34] and concerns about cancer progression [30]. The second most common emotional need included feelings of depression, sadness, dread and post-traumatic stress symptoms [15, 21-23, 30, 33, 35, 37]. Females were noted to have higher levels of anxiety and depression compared to males and the reasons for this are unclear [37].

Psychological distress was another key area of concern [15, 24, 25, 29], which underscored the need for greater support in routine service delivery [15]. The following variables were associated with increased distress scores and included: participants on active surveillance of a biopsy proven malignant tumour [25], neuroticism, a younger age, a lower education level and the use of avoidant coping strategies [29]. It was unclear whether gender predicted higher distress scores. Two publications observed that females had higher levels of distress [24, 29], whereas another publication concluded that there was no difference in distress and gender among kidney cancer survivors [15].

Other areas of emotional need included self-management of emotions [34], feeling irritable or angry [21, 34], feelings of nervousness [15], loss and loneliness [21], as well as mental health disorders (such as adjustment disorder, anxiety disorder and mood disorders) [22].

In contrast, one study found no difference in depression for people affected by kidney cancer compared to the general population control group [27]. Another study found no change in mental health for people affected by kidney cancer over their disease trajectory [31]. One study found that the participants emotional well-being and role limitations due to emotional problems improved from baseline data at both six and twelve months after surgery [32].

Physical needs

Ten publications described unmet physical needs of people diagnosed with kidney cancer [15, 22-24, 27, 28, 30-32, 34]. Pain was the most commonly identified distressing physical need [15, 27, 30, 32, 34], followed by fatigue [22, 23, 28, 30, 34] and sleep disturbances [15, 22, 23, 34]. These needs were identified across studies that included people with both localised and metastatic kidney cancer, however, it was unclear whether these physical consequences were attributed to the cancer, treatment or some other cause, such as existing co-morbidity. Additionally, distress related to the side-effects of treatment and changes in their physical appearance were common in patients affected by metastatic kidney cancer [34].

Additional physical needs included decreased physical functioning/quality of life [27, 31, 32], restricted physical activity and being unable to participate in physical exercise activities which were previously enjoyed [28, 30]. Patients grappled with the side-effects of treatment [23, 34], experienced physical deconditioning after surgery [28] and dyspnoea [27], with little support or intervention offered to them.

The recovery of physical impact of cancer and its treatment had mixed recovery trajectories. Shin et al., found a decrease in physical functioning seen at baseline assessment which had resolved by two years post-surgery [27]. In contrast, five studies observed that fatigue was a key concern for kidney cancer patients over time with different cancer trajectories [22, 23, 28, 30, 34]. However, the findings surrounding fatigue were not consistent throughout all the studies. Novara et al., found that kidney cancer patients diagnosed with both localised and metastatic cancer had improved energy levels from baseline data at both six months and twelve months post-surgery [32]. Thekdi et al., found that when post-traumatic stress symptoms and depression were experienced, patients had worse cancer-related symptoms, in particular fatigue and increased sleep disturbance [23].

Social needs

The social functioning of people with kidney cancer was discussed across three publications [27, 30, 32]. Two publications identified some form of decrease in social functioning [27, 30], while the remaining study found an increase in social functioning [32]. Patients were found to also have a decreased interest in social activities [30]. One study reported an initial decrease in social functioning that improved over two years post-operatively [27].

Interpersonal/intimacy needs

The evidence identified unmet needs related to intimacy, relationships and sex [21, 36]. Christiansen et al., found a statistically significant increase in problems in relation to sexual relationships post-operatively ($p<0.0001$) [36]. Patients experienced decreased interest in sex since diagnosis and approximately 50% ($n=29$) of males in one study reported some degree of erectile dysfunction [36]. A loss of intimacy and a feeling of estrangement from loved ones was also highlighted as problematic, which were not explored with them during clinical consultations [21, 36].

Patient-clinician communication needs

The evidence suggested that there is a room for improvement in patient-clinician communication [30, 34, 36]. Evidence identified a discrepancy between the needs and preferences of the actual communication and information provided to patients and their caregivers before and after surgery, and what they wanted and needed from their clinical care teams [30]. Patients stated they would have liked their clinician to have communicated with them about potential sexual dysfunction as a surgical complication [36]. Furthermore, some patients were worried about becoming too ill to communicate [34]. However, only a small percentage of patients (1.6%) identified that talking with the doctor caused distress [34].

Family related needs

Three publications identified unmet family related needs [32, 34, 36]. Worries about how the patient's family would cope was considered by those living with kidney cancer and caused high distress [34]. Additionally, kidney cancer patients were shown to have significantly decreased SF-36 scores for role limitations due to physical health problems ($p=0.007$) [32]. However, the impact of these role limitations on the family or carer were not explicitly stated.

Health system/information needs

Health system and information needs were important to optimise recovery and helped patients and family caregivers maintain a sense of control [21, 34]. Some people were not provided with the care co-ordination to understand their treatment options, and other people experienced a lack of signposting to community resources which caused distress for some participants [34]. Some reported that having more information about their kidney cancer provided more control and reduced anxiety levels, whereas for others, too much information could be disquieting [21]. Both of these studies were conducted in the United States of America and therefore little is known about the informational needs in different international contexts and locations of services [21, 34].

Spiritual needs

Contrasting views surrounded the role of spirituality for people affected by kidney cancer [21, 28]. Spirituality was identified as both an unmet need as well as a coping strategy. One study found that the overall common theme was “finding meaning from living with cancer from within an awareness of their mortality” [21]. Doubts and fears around faith were expressed [21]. However, other participants spoke of cancer as being a divine blessing, leading to re-evaluation and finding meaning and gratitude in life, and some individuals used faith and prayer as a coping strategy [21, 28].

Daily living needs

Two publications discussed needs related to daily living [28, 34]. Bergerot et al., discussed the distress level associated with various daily living needs [34]. People affected by metastatic kidney cancer often found walking/climbing stairs and eat/chewing/swallowing difficulties to cause high distress [34].The cause of the eating/chewing/swallowing difficulties was not discussed [34] and it was unclear if this related to another existing condition or a side-effect of kidney cancer treatments [39]. A mixed methods study conducted by Ames et al., identified the people living with kidney cancer reported a restricted ability to complete household chores as a major theme [28]. However, the quantitative analysis in this mixed methods study did not reveal any statistically significant changes in any of the quality-of-life measures (including physical functioning) from pre- to post-treatment [28].

Practical needs

Practical needs were only highlighted in one publication which included people living with metastatic kidney cancer [34]. The practical needs were discussed in association with the level of distress that they produced. Practical problems that were identified as causing high distress included: finances, transportation and needing help coordinating care [34].

Cognitive needs

Only one publication discussed cognitive needs of people affected by kidney cancer [27]. Shin et al., found that there was no significant difference ($p=0.747$) in cognitive functioning between patients with kidney cancer and the control group [27].

Needs from the perspective of the partner/caregiver

The partners or caregivers of people diagnosed with kidney cancer had a range of unmet needs which included psychological, intimacy, social, informational, family and spiritual needs. Caregivers experienced heightened levels of anxiety and depression and identified problems with their sex life [33, 36]. Partners of people with kidney cancer found that their sexual interest was impacted since their partners diagnosis and noted frustration with a lack of sex life [36]. Additional unmet needs were around the impact that cancer had on their relationship with the person with cancer [33]. Caregivers had a range of problems related to employment and social needs, a decreased interest in previously enjoyed social activities and expressed spiritual needs [30, 33]. Caregivers also identified unmet informational and healthcare system needs, however those who were in a marital/de facto relationship had significantly lower odds of experiencing unmet information needs [33].

Frequency of supportive care needs as identified in the literature

The frequency of unmet supportive care needs identified (see **Supplementary Table 5** across the included publications) listed in descending order: psychological/emotional needs (17/18: 94%), physical needs (10/18: 56%), social needs (4/18: 22%), interpersonal/intimacy needs (4/18: 22%), patient-clinician communication needs (3/18: 17%), family related needs (3/18: 17%), health system/information needs (3/18: 17%), spiritual needs (3/18: 17%), daily living needs (2/18: 11%), practical needs (1/18: 6%) and cognitive needs (1/18: 6%) (see **Figure 2**).

Discussion

This systematic review set out to identify the unmet supportive care needs of people affected by kidney cancer as well as to identify the most frequently reported individual domain of unmet supportive care need. This review has described the complex unmet supportive care needs of people living with kidney cancer. Whilst this review included people with varying kidney cancer stages and histology types, it was unable to correlate specific unmet supportive care needs with individual clinical variables. Therefore, further research is still required to understand how clinical (stage/treatment) and demographic (age/socio-economic/ethnicity) variables may moderate or mediate the relationship with unmet needs over time.

There was a wide range of unmet supportive care needs experienced by people affected by kidney cancer across the domains. A prominent focus was on psychological and physical needs. Some of the unmet needs, including anxiety, depression and fear related to cancer and reoccurrence have also been highlighted in other cancer patient groups [11, 18, 40]. Pain is a frequently reported need for people with cancer in general [41], and this was a similar finding in this review underscoring the importance of timey, anticipatory and preventative cancer pain management [42]. While pain was identified as an unmet need for people affected by kidney cancer, little information was provided in the studies about the type, location, cause of pain or the clinical characteristics of the participants which made it difficult in the clinical interpretation of these findings. Similarly, fatigue and sleep disturbances were noted as a significant unmet supportive care need for people affected by kidney cancer, and while experienced in other tumour groups these bothersome symptoms have not been the central focus of need of supportive care [11, 18, 40, 43].

Caregivers or partners of people diagnosed with kidney cancer reported their own unmet supportive care needs covering various domains of need. Caregivers experienced problems with their sex life and employment, and identified social, intimacy, informational, health system and spiritual needs [30, 33, 36]. Caregivers also experienced heightened levels of anxiety and depression [33, 36]. Psychological needs have also been identified for caregivers of other tumours groups [44-46]. Informational and healthcare system needs were identified as key unmet needs for caregivers highlighted in this review [44-46]. Only one study in this review focused solely on the unmet needs of caregivers of people with kidney cancer which emphasises the importance for further research in this area to understand their unique needs and concerns [33].

This review included 18 publications over 15 studies and underscores that this is an emerging area of research but still in its infancy. The majority of the included studies had lower levels of evidence with a number of limitations, and signifies the importance of future high-quality research to identify what matters most to people affected by kidney cancer and their family/caregivers to inform future models of service delivery. Importantly, there was little information provided across the included studies about the lived experience of people affected by kidney cancer, with only one qualitative study, and two mixed methods studies being included [21, 28, 36]. Therefore, future research designs might adopt a qualitative methodology to provide 'voice' to people affected by kidney cancer as an important consideration moving forward. Furthermore, most of the study designs were cross-sectional in nature and only provided a snapshot of the unmet supportive care needs experienced and provided little insight into how needs change over the cancer care continuum. Further research into understanding the changing support needs (physical, psychological/emotional, cognitive, patient-clinician communication, health system/information, spiritual, daily living, interpersonal/intimacy, practical, family related and social needs), as well as clinical and demographic variables that may have a relationship with these domains may help identify those individuals at greatest risk of distress to target timely interventions.

The heterogeneous nature of the methodological approaches of the included studies made it difficult to compare the data from the various studies. Only one study made use of the unmet supportive care needs survey [33]. Widespread use of this survey to identify unmet supportive care needs for people affected by kidney cancer would aid in being able to collate data more effectively to provide a deeper understanding of the overall needs of people affected by this disease. A further limitation to the current evidence base is the lack of reporting on comorbidities which may have influenced the experiences of unmet supportive care. Three studies [29, 32, 37] utilised the Charlson comorbidity index [47] to account for comorbidities within their results and one other study captured the major comorbidities reported in the Charlson comorbidity index without using the specific tool [31]. The remaining twelve studies, reported in fourteen publications, did not mention, or specifically stated they had missing data in relation to comorbidities among the participants included in this review [15, 21-28, 30, 33-36].

There are several important clinical implications for this review. This review has highlighted that people affected by kidney cancer can experience a range of unmet supportive care needs among those diagnosed with localised, locally advanced/metastatic disease. Typically, individuals affected by kidney cancer do not have routine access to specialist kidney cancer nurses which are mainstay in other cancer groups, such as prostate cancer and breast cancer [48]. Evidence has demonstrated that disease specific specialist cancer nurses positively impact patient outcomes by delivering holistic nursing care, education, care coordination and clinical expertise safely embedded in the multidisciplinary team [49, 50]. Therefore, an inequality exists internationally in access to specialist kidney cancer nurses which is entangled by financial and political policy drivers. It is critical therefore, that all members of the multidisciplinary team take time to recognise, assess and respond to the holistic person-centred needs and concerns to optimise recovery and physical and psychological rehabilitation [51].

Limitations

This review followed a clear, rigorous, and transparent review process, however there are a number of limitations to highlight. This review included studies which were published in the English language only, and as such publications in other languages might have omitted important information about the experience of unmet supportive care needs. However, the review included evidence from a range of international countries, encompassing diverse populations across all stages of kidney cancer. One of the major challenges of this review was combining heterogeneous methodologies, and our findings are constrained due to the methodological limitations of the studies included. Noteworthy some of the studies included mixed cancer populations, but we only included sub-group analyses provided of patients affected by kidney cancer. A further major limitation was that we were unable to identify specific unmet needs in relation to cancer stage and treatments. Lastly, this review included qualitative and quantitative studies to elicit how unmet needs were expressed by the participants without being necessarily assessed as a primary objective in the included studies, which may have introduced bias. A clear definition of supportive care needs was used to inform this review across international literature as strength to understand the experience of unmet supportive care needs of people affected by kidney cancer globally.

Conclusion

This systematic review has identified that people affected by kidney cancer experience a range of unmet supportive care needs. The most frequently reported domain of need were psychological/emotional and physical needs which requires timely and tailored interventions in care delivery. There has been a dearth of qualitative research to provide a ‘voice’ to people affected by kidney cancer to enable them to articulate what matters most to them. Due to limitations within the individual studies and the infancy of the research there is limited knowledge about how their needs change over time. This review has highlighted important implications for clinical practice and future research directions. For the moment, all members of the multidisciplinary team caring for people affected by kidney cancer are encouraged to use the findings of this review to inform them of the person-centred needs of their patients.

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Title: Identifying the unmet supportive care needs of people affected by kidney cancer: A systematic review

Authors: Amy O'Dea (BTh)[a,c], Craig Gedye (BScHons MBChB FRACP PhD)[f,g,h], Belinda Jago (BBusAcc, Consumer), Catherine Paterson (PhD, BA, MSc, PgCert LTA, FHEA, RAN)[a,b,c,d,e]

[a] Faculty of Health, University of Canberra, Bruce ACT, Australia

[b] Prehabilitation, Activity, Cancer, Exercise and Survivorship (PACES) Research Group, University of Canberra, Bruce ACT, Australia

[c] School of Nursing, Midwifery and Public Health, University of Canberra, Bruce ACT, Australia

[d] Canberra Health Services & ACT Health, SYNERGY Nursing & Midwifery Research Centre, ACT Health Directorate Level 3, Building 6, Canberra Hospital, Australia

[e] Robert Gordon University, Aberdeen, Scotland, UK

[f] Senior Staff Specialist, Calvary Mater Newcastle

[g] Director, HMRI Clinical Trials

[h] Conjoint Associate Professor, School of Medicine and Public Health, University of Newcastle

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Corresponding Author:

Professor Catherine Paterson

Clinical Chair in Nursing

School of Nursing, Midwifery and Public Health, University of Canberra, Bruce ACT, Australia

Email: Catherine.paterson@canberra.edu.au

Telephone: +61 (0)2 6206 8419

Supplementary Table 1. PRISMA checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4 and 5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	We followed a review protocol but this was not published (available from the authors)
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary Tables, table 2 page 4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	N/A
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6

Section/topic	#	Checklist item	Reported on page #
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	5 and 6
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	6
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	6
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	5 and 6
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6 and Figures document, figure 1 page 2 for diagram
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Tables document, table 2: pages 3-9
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Tables document, table 3, page 10
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Supplementary tables, table 3 and 4, pages 6-11
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	6-10
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	6-7
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	10-11
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	11
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	12
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	1

Supplementary Table 2. Electronic database searched and search terms used.

Electronic databases	Search terms
Medline CINAHL PsychINFO	1. “unmet supportive care needs” OR “unmet needs” OR “care needs” OR “patient needs” OR “needs assessment” OR “family needs” OR “caregiver needs” OR “supportive care needs” 2. “health system” OR “health information” OR “patient-clinician communication” OR “cognitive needs” OR “patient care needs” OR “patient care team” OR “multidisciplinary care team” OR “Patient Care Planning” OR “patient care bundles” OR “Patient Care” OR “patient-centered care” OR “person centered care” OR “family centered care” OR “progressive patient care” OR patient care management” OR “continuity of patient care and oncology and palliative and primary care” OR “Continuity of Patient Care” OR “Respite Care” OR “social support” OR “social networks” OR “social relationships” OR “support” OR “training support” OR “financial support” OR “nutritional support” OR (MH “Employment, Supported”) OR “decision support techniques” OR “subacute care” OR “ambulatory care” OR “outpatient” OR “primary care” OR “acute care” OR “inpatient care” OR “hospital care” OR “health planning support” OR “supportive care” OR “behavioural symptoms” OR “symptom assessment” OR “Affective Symptoms” OR “symptom control” OR “symptom management” OR “urinary symptoms” OR (MH “Signs and Symptoms”) OR (MH “Signs and Symptoms, Digestive”) OR (MH “Symptom Distress”) OR (MH “Symptoms”) OR (MH “Sexual Dysfunction, Female”) OR (MH “Sexual Dysfunction, Male”) OR “Sexual Dysfunction” OR “sexuality” OR “sex” OR “intimacy” OR “sexual behaviour” OR “information literacy” OR “information needs” OR “needs assessment” OR “spiritual therapies” OR “spirituality” OR “religion” OR “faith” OR “belief system” OR “spiritual needs” OR (MH “Hospice and Palliative Nursing”) OR “palliative care” OR (MH “Pain”) OR (MH “Pain Measurement”) OR (MH “Pain Management”) OR “palliative” OR (MH “Hospice Care”) OR (MH “Human Needs (Psychology)”) OR (MH “Human Needs (Physiology)”) OR “physical needs” OR “emotional support” OR “emotional needs” OR “family support” OR “family inclusion” OR “family involvement” OR “family engagement” OR “family needs” OR “social needs” OR (MH “Interpersonal Relations”) OR “interpersonal” OR “practical needs” OR “psychological assessment” OR (MH “Activities of Daily Living”) OR “daily living needs” OR “bereavement” OR “grief” OR “loss” 3. 1 or 2 4. “kidney cancer” OR “renal cancer” OR “kidney neoplasm” OR “renal neoplasm” 5. 3 and 4 6. Limit Full-text 7. Limit 2010-2020

Supplementary Table 3. Hierarchy of Evidence used by the Department of Health in the National Service Framework [1]

Typologies of supporting evidence
A1 Systematic reviews, which include at least one randomized control trial (RCT), e.g. systematic reviews from Cochrane.
A2 Other systematic and high-quality reviews.
B1 Individual RCTs.
B2 Individual non-randomized, experimental/interventional studies.
B3 Individual well-designed non-experimental studies, controlling statistically if appropriate. Includes case control, longitudinal, cohort, matched pairs or cross-sectional random sample methodologies, and well-designed qualitative studies, well-designed analytical studies including secondary analysis.
C1 Descriptive and other research or evaluations not in B (e.g. convenience samples).
C2 Case studies and examples of good practice.
D Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified.

Supplementary Table 4. Unmet supportive care needs

Author and Year	**Physical Needs**	**Psychological/Emotional Needs**	**Cognitive Needs**	**Patient-Clinician Communication Needs**	**Health System/Information Needs**	**Spiritual Needs**	**Daily Living Needs**	**Interpersonal/intimacy Needs**	**Practical Needs**	**Family Related Needs**	**Social Needs**
Ajaj et at., 2020	Physical distress was higher in females after biopsy (p=0.028), and after nephrectomy (p=0.022). Physical distress was similar between males and females at diagnosis (p=0.106) and at last follow-up (p=0.519).	Psychological distress was higher in females after diagnosis (p=0.018), after biopsy (p=0.003), and after surgery (p=0.007). Psychological distress was no different between males and females at last follow up (p=0.379).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Ames et al., 2011	Baseline values for energy/fatigue and vigor-activity (M = 69.3 [19.5] and M = 11.8 [4.2], respectively) were higher than values at 4-weeks post nephrectomy (M = 52.0 [24.4] and M = 8.6 [5.0], respectively). Fatigue, physical deconditioning after surgery, restricted physical activity and ability to exercise were themes identified through the interviews.	The sample group had significantly worse functioning (i.e., more mood disturbance) at baseline on all subscales (p < 0.001) than the normative sample. Anxiety about recurrence and whether the surgeon removed all the cancer were themes identified through the interviews.	Not reported.	Not reported.	Not reported.	Prayer/faith was identified as a strategy for coping with renal cancer.	Restricted ability to complete household chores was a theme identified through the interviews.	Not reported.	Not reported.	Not reported.	Not reported.
Beisland et al., 2020	Not reported	Females had higher distress (r=0.19/0.24, p < 0.05/0.01) Neuroticism, a younger age, a lower education and the use of avoidant coping were associated with increased distress.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Bergerot et al., 2019	Physical problems that were endorsed as high distress included: fatigue (48%), pain (39.5%), sleeping (35.6%), side effects of treatment (27.9%) and physical appearance (10.7%). N values not reported for individual problems.	Emotional problems that were endorsed as high distress included: solving problems (21.3%), managing emotions (20.5%), feeling anxious or fearful (19.5%), fear of medical procedures (15%), feeling irritable or angry (12.5%). Poorer overall survival was seen in patients with high distress versus low distress (p=0.09). N values not reported for individual problems.	Not reported.	Becoming too ill to communicate was endorsed as causing high distress for 12.1% of the sample. Whereas, only 1.6% stated that talking with the doctor caused high distress. N values not reported for individual problems.	Understanding treatment options and finding community resources were endorsed as causing high distress by 18.3% and 13.3% of participants respectively. N values not reported for individual problems.	Not reported.	Daily living needs that were endorsed as high distress include: walking/climbing stairs (31.6%) and eating/chewing/ swallowing difficulties (16%). N values not reported for individual problems.	Not reported.	Practical problems that were endorsed as high distress included: finances (43.2%), transportation (26.7%), needing help coordinating care (14.1%). N values not reported for individual problems.	35.6% of patients identified “how will my family cope” as causing high distress. N values not reported for individual problems.	Not reported.

Author and Year	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Communication Needs	Health System/Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/intimacy Needs	Practical Needs	Family Related Needs	Social Needs
Christiansen et al., 2020	Not reported.	Not reported.	Not reported.	Only 5% (n=7) of patients had been informed about potential sexual dysfunction as a surgical complication. Interviewed participants stated they would have liked to receive such information.	Not reported.	Not reported.	Not reported.	61.4% (n=43) of patients worried about their sex life/lack of sex life and 27% (n=19) had negative changes in sex interest since diagnosis. 54.7% (n=29) of sexually active males reported having some degree of erectile dysfunction in the survey and similar findings were obtained in the interviews. A significant difference was observed regarding problems with sexual relationships prior to operation compared after (p<0.0001). Interviews noted a loss of intimacy and concern for their partner.	Not reported.	20.0% (n=14) of partners experienced a change in interest in sexual relationships since diagnosis.	Not reported.
Cohen et al., 2012	Not reported.	23% (N=46, p=0.005) of participants had a CES-D score >= 16, meeting the criteria for depressive symptoms.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Draeger et al., 2018	Main stressors included: pain (27%, n=20) and sleep difficulties (20%, n=15).	The distress thermometer identified 47.3% (n=35) of patients having a significant need for psychosocial support, which was significantly different to self-reported need for support (p<0.001). Males and females had similar stress levels. Main stressors included: anxiety (28%, n=21), nervousness (26%, n=19) and sadness (20%, n=15).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Goldberg et al., 2020	Not reported.	Patients treated with active surveillance (AS) with a biopsy proven malignant tumour had worse psychological distress compared to patients treated with surgery/ablation after biopsy (p=0.035) and at last follow up (p=0.004).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.

Author and Year	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Communication Needs	Health System/Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/intimacy Needs	Practical Needs	Family Related Needs	Social Needs
Leal et al., 2018	Not reported.	Some key words and phrases related to emotional/ psychological needs: depression, loss, worrying, so alone, "overwhelming dread which hangs over your head", "bury my feelings of frustration, anger, and loss."	Not reported.	Not reported.	Some participants found that receiving more information about their condition relieved anxiety. Whereas, for others being informed about cancer could be disquieting.	Doubts and fears around faith were expressed. Finding meaning in living with cancer from within an awareness of their mortality was a uniting theme.	Not reported.	Some participants felt estranged from loved ones, one participant stated: "I don't ever talk to my family and friends about this because they just won't talk about it."	Not reported.	Not reported.	Not reported.
Mehnert et al., 2014	Not reported.	36.36% of kidney cancer patients had a mental disorder at 4 weeks. 15.70% of patients had an adjustment disorder, 13.22% an anxiety disorder and 8.26% any mood disorder.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Milbury et. al., 2014	36.1% of patient's experienced clinical levels of fatigue, and 57% reported sleep disturbances. N values not reported.	20.5% of patient's met the criterion for depression. N values not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Moretto et al., 2014	Patient/caregiver identified physical concerns: fatigue (78%), aches (45%), decreased interest in previously considered enjoyed activities (40%). 87% of patients/caregivers were affected in at least one of these domains (physical/emotional), while urologists estimated that about 30% of patients/caregivers would be affected. N values not reported, percentage values are approximate.	Patient/caregiver identified psychological concerns: fear of recurrence (80%), anxiety (76%), concerns about cancer (73%), depression (50%). N values not reported, percentage values are approximate.	Not reported.	Urologists identified that they had provided patients detailed information about their cancer before (93%) and after (98%) surgery. Patients/caregivers "wished their urologists had given more information" before (51%) and after (62%) surgery. N values not reported, percentage values are approximate.	Not reported.	Not reported.	Not reported.	20% of patient/caregivers identified a reluctance to start new relationships. N values not reported, percentage values are approximate.	Not reported.	Not reported.	40% of patients/caregivers identified a decreased interest in previously enjoyed social events compared to only 5% of urologists. N values not reported, percentage values are approximate.
Novara et al., 2010	At 12months, patients had significantly decreased bodily pain score than baseline ($p<0.001$), indicating decreased function in this domain. Patients at 12 months had a higher energy/fatigue score ($p=0.038$), indicating increased well-being in this domain.	At 12months, patients SF-36 score improved for emotional wellbeing and role limitations due to emotional problems ($p<0.001$).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	At 6 and 12 months, patients had a significantly lower SF-36 score for role limitations due to physical health problems, indicating lower functioning than baseline ($p=0.007$).	At 12 months, social function scores had improved significantly ($p<0.001$).

Author and Year	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Communication Needs	Health System/ Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/intimacy Needs	Practical Needs	Family Related Needs	Social Needs
Oberoi et al., 2016	Not reported.	47% (n=92) of caregivers identified at least one unmet psychological or emotional need, with 30% (n=59) identifying a moderate/high need. 29% (n=57) of caregivers reported 10 or more unmet needs. 29% (n=57) of caregivers had elevated anxiety and 11% (n=22) had elevated depression.	Not reported.	Not reported.	42% (n=82) of caregivers identified at least one unmet healthcare system need with 30% (n=59) identifying a moderate/high need. Caregivers who were in a marital/de facto relationship had 80% lower odds of experiencing unmet information needs. 29% (n=57) of caregivers identified at least one unmet information need with 18% (n=35) identifying a moderate/high need. Higher unmet information needs were associated with elevated likelihood of anxiety and depression.	5.6% (n=16) of caregivers identified an unmet need around exploring their spiritual beliefs, with 3.1% (n=5) identifying a moderate/high need.	Not reported.	18.9% (n=37) of caregivers identified an unmet need around the impact that cancer has had on their relationship with the person with cancer. 6.6% (n=13) of caregivers identified an unmet need around addressing problems with their sex life.	Not reported.	Not reported.	40% (n=78) of caregivers identified at least one unmet work or social need with 23% (n=45) identifying a moderate/high need.
Packiam et al., 2020	Not reported.	10% (n=197) of patients were diagnosed with anxiety or depression. Patients with anxiety or depression had increased 30day post-operative complications (p=0.001) and worse survival rates (p=0.065). Females had higher rates of anxiety or depression (p=0.001).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Parker et al., 2013	Patients had worse physical related quality of life at 24 months (p=0.018).	Mental health related quality of life did not change significantly over 24 months.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Shin et al., 2019	KC survivors had significantly lower physical functioning 1-2 years post-surgery (p<0.05), however this resolved over time. KC survivors had higher pain and dyspnoea	No significant difference in depression for KC cancer survivors compared to control group.	No significant difference (p=0.747) in cognitive functioning for KC cancer survivors compared to control group.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	KC survivors had significantly reduced social functioning 1-2 years post-surgery (p<0.05), however this resolved over time.

Author and Year	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Communication Needs	Health System/ Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/intimacy Needs	Practical Needs	Family Related Needs	Social Needs
Thekdi et al., 2015	Patients with PTSS and/or depressive symptoms had significantly worse overall cancer-related symptom severity, fatigue and greater sleep disturbance than patients without PTSS and/or depressive symptoms.	15.2% of patients had comorbid PTSS and depressive symptoms, 24.1% PTSS alone, 5.9% depressive symptoms alone. N values not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.

Posttraumatic Stress Symptoms (PTSS)

Supplementary Table 5. Frequency of unmet needs by domain

Study	Physical Needs	Psychological/ Emotional Needs	Cognitive Needs	Patient-Clinician communication	Health System/ Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/ Intimacy Needs	Practical Needs	Family Related Needs	Social needs	Number of domains explored within each study
Ajaj et at., 2020	✓	✓	-	-	-	-	-	-	-	-	-	**2**
Ames et al., 2011	✓	✓	-	-	-	✓	✓	-	-	-	-	**4**
Beisland et al., 2020	-	✓	-	-	-	-	-	-	-	-	-	**1**
Bergerot et al., 2019	✓	✓	-	✓	✓	-	✓	-	✓	✓	-	**7**
Christiansen et al., 2020	-	-	-	✓	-	-	-	✓	-	✓	-	**3**
Cohen et al., 2012	-	✓	-	-	-	-	-	-	-	-	-	**1**
Draeger et al., 2018	✓	✓	-	-	-	-	-	-	-	-	-	**2**
Goldberg et al., 2020	-	✓	-	-	-	-	-	-	-	-	-	**1**
Leal et al., 2018	-	✓	-	-	✓	✓	-	✓	-	-	-	**4**
Mehnert et al., 2014	-	✓	-	-	-	-	-	-	-	-	-	**1**
Milbury et. al., 2014	✓	✓	-	-	-	-	-	-	-	-	-	**2**
Moretto et al., 2014	✓	✓	-	✓	-	-	-	✓	-	-	✓	**5**
Novara et al., 2010	✓	✓	-	-	-	-	-	-	-	✓	✓	**4**
Oberoi et al., 2016	-	✓	-	-	✓	✓	-	✓	-	-	✓	**6**
Packiam et al., 2020	-	✓	-	-	-	-	-	-	-	-	-	**1**
Parker et al., 2013	✓	✓	-	-	-	-	-	-	-	-	-	**2**
Shin et al., 2019	✓	✓	✓	-	-	-	-	-	-	-	✓	**4**
Thekdi et al., 2015	✓	✓	-	-	-	-	-	-	-	-	-	**2**
Number of domains explored across all studies	**10**	**17**	**1**	**3**	**3**	**3**	**2**	**4**	**1**	**3**	**4**	

References

1. Department of Health, *Typologies of Supporting Evidence.* 2001.