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REVIEW

Identifying the unmet supportive care needs of individuals affected by testicular cancer: a systematic review

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Abstract

Purpose To critically appraise studies to identify experiences of unmet supportive care needs of individuals affected by testicular cancer.

Methods A registered priori systematic review was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. CINAHL, PsycINFO, and MEDLINE were searched for quantitative, qualitative, and mixed methods studies using a wide range of search terms. All articles were double screened according to a pre-determined eligibility criterion. Reference lists of the final included studies were checked for further eligible studies. The review process was managed using Covidence systematic review software. Data from the studies were extracted, methodological quality appraisal conducted, and a narrative synthesis conducted.

Results Of the 72 papers identified, 36 studies were included. In descending order of frequency of need, psychological needs were identified in 26/36, physical needs 18/36, interpersonal/intimacy needs 19/36, health system/information needs 11/36, cognitive needs 9/36, social needs 7/36, and of equal frequencies counts of 4/36 for family, practical, and patient-clinician information needs. Only one study explored spiritual needs and no daily living needs were identified.

Conclusions The experience of needs varied in terms of frequency and distress which were commonly influenced by the age of the individual across the cancer care continuum persisting after 1-year post-treatment.

Implications for Cancer Survivors When caring for individuals affected by testicular cancer, clinicians are encouraged to take a holistic lens to cancer care, particularly to explore issue or concerns that young men affected by testicular cancer might be embarrassed or reticent to discuss.

Keywords Patient care · Supportive care needs · Testicular cancer · Testicular neoplasm · Integrative review · Systematic

Introduction

Testicular cancer is the 26th most commonly diagnosed cancer worldwide [1]. Evidence has underscored that testicular cancer is the most prevalent type of cancer diagnosed among young men aged 15–35 years [2] with 74,458 cases diagnosed globally in 2020 [3]. Testicular cancer is highly curable with survival rates estimated above 90% largely attributed to the introduction of platinum-based chemotherapies [4] resulting in an increased number of survivors. Treatments include orchiectomy, retroperitoneal lymph node dissection, chemotherapy, and radiotherapy, [5] all of which are associated to their own unique profile of concerns with implications for rehabilitation and supportive care [6].

Supportive care is defined as a holistic term used to describe a person-centred approach to the delivery of oncology services for individuals diagnosed with cancer to meet their informational,

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spiritual, psychological, social, or physical needs across the cancer care continuum [7]. Healthcare professionals and researchers have a growing awareness of the importance to identify gaps in supportive care experiences for people affected by cancer. Though the timely identification of unmet needs, planning and delivery of cancer services can be targeted to improve patients' overall health-related quality of life and recovery [7]. To date, a growing number of systematic reviews have examined the unmet needs in various cancer populations such as prostate [8], bladder [9], gynaecological [10], kidney [11], penile [12], breast [13], and colorectal [14], including older populations affected by cancer [13]. However, none of these existing evidence synthesis studies provides any clinical insight into the unique needs of young men affected by testicular cancer [6, 15, 16]. The life expectancy among men diagnosed with testicular cancer is about 30–50 years after treatment. Due to high survival rates, minimising the adverse effects of treatment is a major issue and of central importance. Unmet supportive care needs are associated with quality-of-life outcomes in people with cancer, and therefore, supportive care is considered a modifiable factor for research and service provision [17].

Evidence has demonstrated that men affected by testicular cancer commonly report at least one unmet supportive care need despite routine clinical follow-up [15, 16, 18]. Moreover, unmet supportive care needs have been reported to persist up to 1 year after treatment and correlate with anxiety and depression [19]. These young men may have enduring physical and psychological needs related to diagnosis and treatments comparative to their youth. Existing studies have reported enduring and long-lasting effects from treatment which include problems related to infertility, altered neurological and respiratory function, problems in securing life insurance and employment, psychological distress (such as fear of cancer recurrence), altered masculinity/body image, concerns related to chemotherapy-induced alopecia, and challenges with intimacy and relationships [6, 7, 15, 16, 19]. Physical needs are prevalent in testicular cancer survivors, who on average may experience 4.5 physical symptoms (SD = 4.4; range, 1–28) [20]. Existing studies have identified that the physical needs among testicular cancer survivors are associated with unemployment, age, low socioeconomic status, and anxiety and depression [20, 21]. Furthermore, the psychological/emotional needs of individuals affected by testicular cancer were also found to be high with on average 1.4 psychological unmet needs [20]. Emotional needs are related to emotional functioning, depression [22], hopeless coping style [23], and cancer-related masculinity threat [24]. Several studies [6, 8, 16, 18, 19] have been conducted to explore the unmet supportive care needs of men affected by testicular cancer. To date, there has not been a systematic review to critically appraise the existing evidence to identify the classification of supportive care needs among men affected by testicular cancer to inform the planning and development of cancer services.

Research questions

This systematic review set out to address the following research questions:

1. What are the unmet supportive care needs of individuals affected by testicular cancer?
2. What are the most frequently reported individual domains of unmet need in individuals affected by testicular cancer?

Methods

Design

This integrative systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [25, 26] (see supplementary Table 1). This review also followed a registered priori systematic review protocol available from: PROSPERO: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=292072.

Eligibility criteria

Types of studies

Inclusion:

- All qualitative, quantitative, and mixed methods studies irrespective of research design.
- All studies published in the English language within the last 10 years.

Exclusion:

- Commentaries, editorials, and studies where unmet supportive care needs are not reported were excluded.

Types of participants

Inclusion:

- Participants diagnosed with testicular cancer, irrespective of cancer stage or treatment.
- Studies conducted with patients in mixed cancer groups, except where separate subgroup analyses of only testicular cancer participants were reported.

Types of outcomes

Inclusion:

The primary outcome of this review was non-oncological outcomes related to unmet supportive care needs. The Supportive Care Needs Framework [27] guided the classification of supportive care needs. Outcomes specifically are related to the measurement of unmet supportive care needs (e.g. the Supportive Care Needs Survey [28]) and qualitative experiences, informed by the definition of supportive care (see Table 1 for classification).

Literature search

The APA PsycINFO, CINAHL, and MEDLINE databases were searched in November 2021 for relevant studies published from 2002 onwards. To capture as many studies as possible, the database search architecture utilised a wide range of keywords and subject headings. Limiters were placed on all searches for peer-review and English language. A full record of the database searches is included in Supplementary Table 2. The reference lists of all the articles included were searched to locate additional relevant studies. Citations were managed with Endnote 20 and imported into Covidence systematic review software to facilitate the study selection process.

Selection of studies

Following de-duplication, titles and abstracts were double screened independently by reviewers for eligibility, and any disagreements were resolved by discussion. Full texts were then retrieved, double screened by reviewers, and linked multiple records of the same study together. Any

Table 1 Classification of supportive care needs

Domain of need	Description
Physical needs	Experience of symptoms such as fatigue, pain, etc.
Psychological/emotional needs	Experience of depression, anxiety, sadness, fear, distress, etc.
Cognitive needs	Individual experience of cognitive impairment or decline, memory problems, etc.
Patient-clinician communication needs	Quality of communication and co-ordination between patients and health care professionals, shared decision making, etc.
Health system/information needs	Information needs, uncertainty of follow-up, lack of information about diagnosis and treatment, etc.
Spiritual needs	Fear of death and dying, fears regarding the afterlife, etc.
Daily living needs	Experience of restrictions to daily living, exercise, housekeeping, etc
Interpersonal/intimacy needs	Experience of difficulties with body image, masculinity, sexual dysfunction, compromised intimacy with partner, etc.
Practical needs	Related to daily task restrictions, employment, accessing benefits, life insurance, etc.
Family related needs	Experience of fears/concerns of the family, dysfunctional relationships, etc
Social needs	Experience of reduced social support, social isolation, loneliness, lack of peer support, etc

disagreements were resolved by discussion. The process of the selection of studies was conducted in Covidence systematic review software.

Data extraction and management

Data extraction was performed on the retained full-text studies meeting the inclusion criteria. The data was extracted by one reviewer and independently quality checked by a second reviewer. The data extraction tables were developed and tested on a small sample of studies and then further refined through discussion among the reviewers. The first table of data extraction included information on the purpose, setting, country, sample size, participant characteristics, sampling used, response rate, attrition, design, time points, and data collection tools. The second data extraction table related to the supportive care needs outcome data according to the classification of supportive care needs (see Table 1).

Assessment of risk of bias in included studies

The final retrained full-text studies all underwent a methodological quality assessment. None of the studies was excluded based upon their methodological quality score to enable a comprehensive overview of the current state of the evidence. The methodological quality assessment was conducted using the Mixed Methods Assessment Tool (MMAT) [29]. The MMAT tool was selected because it enables a plethora of study designs to methodological appraised given the integrative review design. This assessment tool enables critical appraisal of all qualitative, quantitative, and mixed methods studies. Each domain of assessment is rated against, “no”, “yes”, and “unclear”. Methodological quality assessment was performed by one reviewer and quality checked by a second reviewer.

Data synthesis

This integrative review used a narrative synthesis [30]. The steps in the narrative synthesis involved (1) data reduction by tabulation, (2) data comparison between studies, and finally, (3) drawing conclusions. This process involved reading the full papers multiple times, linking together similarities and differences between the studies, and quality checking with the primary sources. The data reduction involved delineation of the classification by domain of unmet need within the tabulated data. The data comparison phase involved the reviewers’ identifying patterns and themes through counting and clustering and making comparisons and contrasting the study findings. Finally, the drawing of conclusions and verification involved a subgroup analysis to inform a comprehensive understanding of the topic, which was verified with the primary sources data for accuracy throughout the process. The data synthesis was conducted by two reviewers and consulted with a third reviewer. The reviewers were multidisciplinary healthcare professionals in cancer care.

Results

The initial search yields 2383 results (see Fig. 1). A total of 72 full-text articles were assessed, and 36 articles were excluded with reasons (see Fig. 1). A total of 36 studies fully met the inclusion criteria of which there were five qualitative [21, 31–34], 30 quantitative [15, 18, 20, 22–24, 35–58], and one mixed methods [59] which underscores that this is a developing evidence base (see Table 2). Studies were conducted in the UK (5), the USA (5), Canada (4), Germany (4), Norway (4), Australia (3), Denmark (2), Italy (2), the Netherlands (2), Turkey (2), Greece (1), Lebanon (1), Serbia (1), and Sweden (1). The sample sizes of the included studies varied widely; 16 studies had < 100 participants, 17 studies had ≥ 100 participants, two studies had > 500 participants, and one failed to report how many participants were included [33]. The average age of study participants varied from 25.1 to 44.4 years, and most of the participants had localised disease compared to metastatic disease. Treatments also varied, but most participants were treated by either orchiectomy or orchiectomy and chemotherapy. Although some underwent surveillance, radiotherapy, and/or retroperitoneal lymph node dissection (RPLND) were reported, most of the participants were married, were in full-time employment, and had at least secondary education or higher. Therefore, the participants in this review are not representative of other minority groups (see Table 3 for the results of the methodological quality assessment). Most of the studies were cross-sectional in design and therefore provide little information about how supportive care needs change over time. The studies had small sample sizes and used convenience sampling approaches.

Frequency of unmet supportive care needs

The frequency of unmet supportive care needs varied within and between studies (see Table 4). In descending order of frequency of need, psychological needs were identified in 26/36, physical needs 18/36, interpersonal/intimacy needs 19/36, health system/information needs 11/36, cognitive needs 9/36, social needs 7/36, and of equal frequencies (4/36) for family, practical, and patient-clinician information needs. Only one study explored spiritual needs [51], and no daily living needs were identified.✓

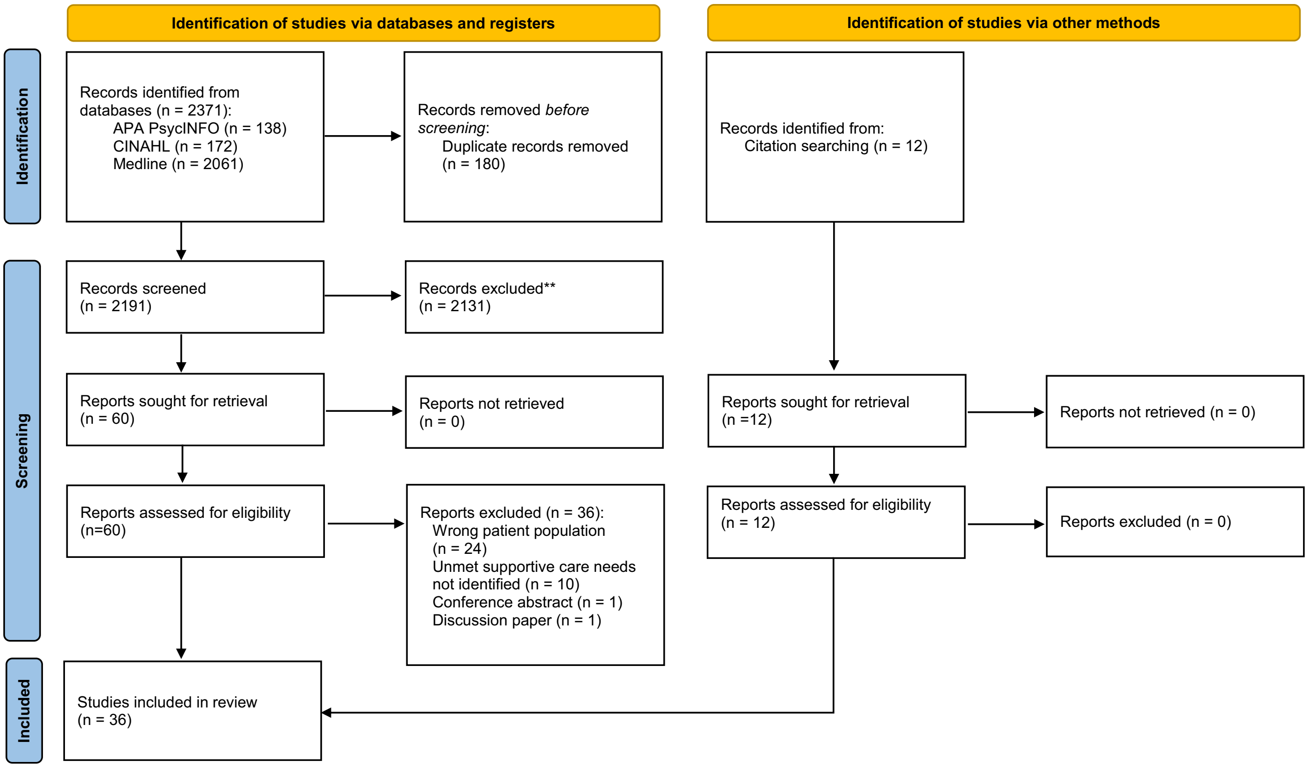


Fig. 1 PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers, and other sources

Unmet supportive care needs by domain

Psychological/emotional needs

Individuals affected by testicular cancer commonly reported unmet psychological/emotional needs. Stress [15, 23, 36, 37], anxiety [23, 43, 45, 51, 53, 54, 57], depression [23, 39, 43, 45, 54], fear of recurrence [23, 37, 38, 41, 59], and body image issues [15, 32, 37, 38, 52, 58] were commonly experienced. Timely intervention for emotional support [23, 32, 37, 59], coping with threats to masculinity [23, 24, 31] and counselling for issues about infertility were needed [32, 33]. Men were embarrassed to disclose concerns about the signs and symptoms of testicular cancer [31], sexual functioning [34], and apprehension to share their diagnosis to the people in their lives [21, 33]. Other challenges included their own self-regulation of managing their own expectations of being a "cancer survivor" [15, 23, 37], how to move on with their lives [15, 23, 37], a lack of emotional support [15, 23], and sadness [20, 32]. Overall, studies reported negative impacts on mental health, reduced emotional functioning, low mental component summary scores [23], and reduced emotional vitality [39].

> "…the bounce back from this was something that I couldn't cope with emotionally because I've never really dealt with a lot of emotions … I'm a guy … you need to be strong and that's what I was taught and you just deal with it and suck it up …" (page e16) [59]

Physical needs

Across the studies, there were a range of physical needs which required self-management support from healthcare professionals. Commonly, testicular cancer survivors experienced fatigue [20, 39, 41, 59], lack of energy [20, 54], drowsiness [20, 54], pain [20, 23, 43], hair loss [15, 20], and sleep disturbances [20, 54]. Men grappled with chemotherapy-induced alopecia and reported needing help with hair loss, but was not provided with any support or education on preventative strategies, such as scalp-cooling [15].

> "Losing my hair was probably more devastating than losing my testicle I think. Because I went from liking my hair to having none in about three days. And that was a big adjustment. Even though a lot of guys you see on the street shave their head, and have short hair when it first happened midway through the chemotherapy … I hadn't shaved in three or four days or

Table 2 Overview of the included studies

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Alacacioglu et al., [22]. Turkey	To determine the prevalence of anxiety depression and sexual satisfaction in TCS and compare rates with healthy controls.	Izmir Katip Celebi University Atatürk Research and Training Hospital Clinic, Medical Oncology.	N=41 N=38 healthy controls.	**Clinical:** 39% had a family history of cancer. No further details reported. **Demographics:** Mean age (range): 38 (26-42). post-graduate education: 24.4%.	Convenience	Not reported.	N/A.	Cross sectional survey.	1.	**Questionnaires:** Demographics: Unspecified questionnaire. Depression and anxiety: Hospital Anxiety and Depression Scale (HADS). Sexual functioning: Golombuk-Rust of Sexual Satisfaction (GRISS). Quality of life: European Organisation for Research of Treatment of Cancer Questionnaires Quality of Life – C30 (EORTC-QoL-C30).
Amidi et al., [35]. Denmark	To investigate the experiences of cognitive impairment post-treatment in TCS.	Department of Oncology, Aarhus University Hospital.	N=66. N=25 healthy controls.	**Clinical:** Unilateral orchiectomy – 100% (N=66). I – 70% (N=46). II – 26% (N=17). III – 4% (N=3). **Demographics:** Mean age (SD) - 36.8 years (10.9). Mean number of years of education (SD) – 14.2 (2.3).	Convenience	70%.	N/A.	Cross sectional survey.	1.	**Questionnaires and clinical data:** Reaction time: MOART Reaction and Movement Time Panel. Processing speed: Wechsler Adult Intelligence Scale version 4 (Ws6AIS-IV)—Coding Trail-Making Test Part A (TMT-A). Attention and working memory: WAIS-IV—Digit span and the Paced Auditory Serial Addition Test (PASAT). Verbal learning and memory: Rey Auditory Verbal Learning Test (RAVLT). Verbal fluency: Controlled Oral Word Association (COWAT). Executive functioning: Trail-Making Test Part B (TMT-B) Wisconsin Card Sorting Test (WCST). Premorbid intelligence functioning: WAIS Vocabulary subtest. Psychological distress: The Hospital Anxiety and Depression Scale (HADS) Perceived Stress Scale (PSS). Post-traumatic stress symptoms: Impact of Events Scale—Revised (IES-R). Cognitive complaints: Cognitive Failures Questionnaire (CFQ). Medical variables: Extracted from medical records. **Biological data:** Serum cortisol, Plasma interleukin-6, Tumour Necrosis Factor alpha, C. reactive protein.

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Amidi et al., [36] Denmark.	To determine the frequency of cognitive impairment in TCS.	1 – The Department of Oncology, Aarhus University Hospital.	N=72.	**Clinical:** Chemotherapy - (3/4 cycles, BEP) 50% (N=36). No chemotherapy – 50% (N=36). Radiotherapy – 18.1% (N=13). No radiotherapy – 81.9% (N=59). I –43.1% (N=31). II – 44.4% (N=32). III – 8.3% (N=6). IV – 4.2% (N=3). **Demographics:** Mean age (SD [range]) – 40.1 (9.7) [24 -70]. Mean years of education (SD) [range] – 13.3 (3.0) [7-18].	Convenience	31.2%.	N/A.	Cross sectional survey.	1.	**Questionnaires:** Attention and working memory: Wechsler Adult Intelligence Scale III Digit Span. Wechsler Adult Intelligence Scale III Letter-Number Sequencing. Wechsler Adult Intelligence Scale III Arithmetic. Processing speed: Wechsler Adult Intelligence Scale III Coding. Wechsler Adult Intelligence Scale III Symbol Search. Trail Making Test – Part A. Verbal fluency: Primary Mental Abilities Test. Verbal learning and memory: Rey Auditory Verbal Learning Test. Visual learning and memory: Rey Complex Figure and Recognition Trial (1st trial). Rey Complex Figure and Recognition Trial (total). Executive functioning: Trail Making Test – Part B.
Batehup et al., [37] UK	To investigate the unmet supportive care needs of survivors of breast, colorectal and testicular cancers and determine their frequency.	Not reported.	N=75 at T0. N=41 at T2.	**Clinical:** Surgery only – 14.9% (N=13). Surgery and chemotherapy – 80.5% (N=70). Surgery and radiotherapy - 3.4% (N=3). Chemotherapy only – 1.1% (N=1). **Demographics:** Mean age (SD) – 39.1 (12.2).	Convenience	72%.	44.8% at T2 (8 months).	Prospective longitudinal survey.	4	**Questionnaire:** Unmet supportive care needs: Modified 25 question Cancer Survivors Unmet Needs Survey (CaSUN).
Bender et al., [15] Canada	To investigate the unmet supportive care needs of TCS, assess TCS preferences for receiving online support	1 - Princess Margaret Hospital, Toronto.	N=204.	**Clinical:** Surveillance – 55.9% (N=114) Radiation – 8.3% (N=17) Chemotherapy – 17.6% (N=36) RPLND – 2.5% (N=5) Chemotherapy and RPLND - 14.7% (N=30) Radiation and chemotherapy – 0.5% (N=1) Radiation, chemotherapy and RPLND – 0.5% (N=1) **Demographics:** Mean age (SD) – 35.6 (10.5).	Convenience	71.3%.	N/A.	Cross sectional survey.	1	**Questionnaire:** Sociodemographic characteristics: Age, Education, Income, Employment status, Place of birth, First language. Unmet supportive care needs:Altered version of the Cancer Survivors Unmet Needs (CaSUN) instrument. Use of computers, the internet and social media: “Seven categorical and three-point response (yes, no, unsure) questions developed based on previous research by investigators JLB and DW.”

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Brand et al., [38] UK	To evaluate the effect of active surveillance of testicular cancer on the sexual functioning of people	Not specified.	N=21.	**Clinical:** Stage one germ cell testicular cancer with or without lymphovascular invasion -21 people (100%). Orchiectomy – 100% (N=21). **Demographics:** Not reported.	Convenience	Not specified.	N/A.	Prospective longitudinal study.	2	**Two-part questionnaire:** Part 1: Sexual function: “Introductory questions”. Brief Male Sexual Function Inventory for Urology. Part 2: Information seeking:
Bumbasirevic et al., [39] Serbia	To investigate sexual functioning, physical symptoms, HRQoL, and depression among TCS	1 - Clinic of Urology, Clinical Center of Serbia.	N=202.	**Clinical:** Radical orchiectomy and adjuvant chemotherapy - 91.5% (N=185). Radical orchiectomy adjuvant chemotherapy retroperitoneal lymph node dissection - 8.5% (N=17). **Demographics:** Age not reported.	Convenience	96%.	N/A.	Cross sectional study	1.	**Questionnaires:** Health related quality of life: Short Form 36 (SF-36) European Organization for Research Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). Feeling and attitudes to general depressive status: The Beck Depression Inventory (BDI). Sexual functioning: Generic questionnaire comprising of nine yes/no answer questions about erectile and ejaculatory function, sexual drive, assessment of sexual life before and after treatment.
Carpentier et al., [31] USA	To explore the romantic and sexual relationships of young people after their experience with testicular cancer.	1 - Indiana University Simon Cancer Center.	N=21.	**Clinical:** Treatment not reported. **Demographics:** Age (mean): 27.1 years.	Purposive	Not specified.	N/A.	Phenomenological study.	1.	**Semi structured interview:** Based on Ferrell et al’s model of quality of life in cancer survivorship. Questions focused on: social and relational quality of life.
Darabos and Hoyt, [40] USA	To investigate future worry in the context of perceived stress	Not specified.	N=171.	**Clinical:** Radical inguinal orchiectomy – 73.1% (N=125). Bilateral orchiectomy – 7% (N=12). Retroperitoneal lymph node dissection – 24% (N=41). Chemotherapy – 53.2% (N=91). Radiation – 15.2% (N=26). Other – 8.2% (N=14). **Demographics:** Mean age (SD)- 25.21 (3.33).	Convenience	59%.	Not specified.	Cross sectional study.	1.	**Questionnaire:** Cancer related worry: Two-item future perspective subscale of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire for Testicular Cancer (EORTC QLQ-TC26). Perceived stress: 10-item Perceived Stress Scale. Physical wellbeing: Seven-item physical well-being Subscale of the Functional Assessment of Cancer Therapy General (FACT-G).
De Padova et al., [41] Italy	To explore the perceptions of TCS and their carers regarding survivorship and compare them to the perceptions of healthcare providers.	1 - Istituto Tumori Romagna – IRST.	Patients – N=29. Carers – N=14. Healthcare providers – N=42.	**Clinical:** Surveillance – 21% (N=6). CT +/- RT +/- RPLND – 66% (N=19). RT only – 7% (N=2). RPLND only – 3% (N=1). Not answered – 3% (N=1). **Demographics:** Median age (range) - 36 (22- 60).	Convenience	Patients – 91% (20/32). Carers – 100% (14/14). Healthcare providers – 70% (42/60).	N/A.	Cross sectional survey.	1.	**Questionnaire:** Author developed questionnaire investigating: demographics, quality of life, role of healthcare providers/ services.

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Dimitropoulos et al., 2016 Greece	To evaluate the sexual functioning of patients who were treated with retroperitoneal lymph node dissection post chemotherapy before and after treatment.	1 - Department of Urology, University Hospital od Larissa, Greece.	N=63.	**Clinical:** Time interval from last chemotherapy to PC-RPLND (weeks) - 6.2 (3.86). IIB – 7.5% (N=4). IIC – 28.3% (N=15). IIIA – 3.8% (N=2). IIIB – 50.1% (N=27). IIIC – 9.4% (N=5). **Demographic:** Mean age at diagnosis (SD): 30.4 (7.89).	Convenience	N/A.	Not reported.	Prospective longitudinal.	2.	**Questionnaires:** Sexual function: International Index for Erectile Function (IIEF). Demographics, medical History, sexual functioning
Kerns et al., [43] USA, UK and Canada	To analyse the relationship between cisplatin related adverse events and self-rated health, unemployment and disability in TCS	8 - University of Rochester, University of Pennsylvania, Indiana University, Dana Farber Cancer Institute, Memorial Sloan Kettering Cancer Center, M.D. Anderson), Princess Margaret Hospital and British Columbia Cancer Agency	N=1815.	**Clinical:** Seminoma – 24.6% (N=447). Non-seminoma or mixed germ cell tumour – 73.2% (N=1328). Germ cell tumour not otherwise specified – 2.2% (N=40). RPLND: Yes - 46.5% (N=836). No – 53.5% (N=962). **Demographics:** Median age: 37 (18 – 75)	Convenience	Not reported.	N/A.	Cross sectional.	1.	**Questionnaires:** Neuropathy: European Organization for Research and Treatment of Cancer Chemotherapy-Induced Peripheral Neuropathy (EORTC CIPN-20). Neurotoxicity: Scale for Chemotherapy-Induced Neurotoxicity (SCIN). Adverse events: Terminology Criteria for Adverse Events. Physical activity: Minnesota LTA questionnaire.
Martin et al., [21] UK	To describe the needs of TCS	Southampton General Hospital.	N=24	**Clinical:** Not reported. **Demographic:** Not reported.	Convenience	Not reported.	N/A.	Qualitative	4	Needs assessment participants were asked for “reasons why survivorship care services need to be improved, as well as causes of that antecedent” and a logic map created.
Matheson et al., [32] UK	To explore young men’s adjustment to survivorship of testicular cancer.	Three NHS hospitals in the south of England.	N=18.	**Clinical:** Surgery alone – 33% (N=6). Surgery + chemotherapy/or radiotherapy – 67% (N=12). **Demographics:** 20 – 24 years – 11% (N=2). 25 – 29 years – 17% (N=3). 30 – 34 years – 22% (N=4). 35 – 39 years – 22% (N=4). 40 – 45 years – 28% (N=5).	Convenience	33%.	22.2222%.	Longitudinal qualitative.	2	Semi-structured interviews
Nord et al., [44] Sweden	To determine if TCS experience more work loss	Not reported.	2146 people with testicular cancer. 8448 people in comparison group.	**Clinical:** Surveillance – 29% (N=605). Radiotherapy – 14% (N=300). Chemotherapy [1 course] – 29% (N=621). Chemotherapy [2 – 3 courses] – 6% (N=118). **Demographics:** Median age: 32.	Convenience	Not reported.	N/A.	Cohort	1.	Data from SWENOTECA (Swedish Norwegian Testicular Cancer Group) database, Causes of Death Register, Statistics Sweden and Social Insurance Agency database.

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
O'Carrigan et al., [45] Australia.	To examine the frequency of abnormal serum hormone levels in TCS and determine if the presence if hormone levels is associated with quality of life or psychological health.	Multiple centres (details unspecified).	N=100.	**Clinical:** Surgery – 94% (N=51). Chemotherapy – 72% (N=39). Radiotherapy – 15% (N=8). **Demographics:** Median age (years) (range) – 35 (19-64)	Convenience	N/A.	N/A.	Cross sectional survey.	1.	**Biological data:** Serum testosterone, serum follicle stimulating hormone, luteinizing hormone. **Questionnaires:** Depression and anxiety: Hospital anxiety and depression scale (HADS). Fatigue: Functional Assessment of Chronic Illness Therapy – Fatigue (FACTIF-F)
Oechsle et al., [20] Germany.	To investigate what symptoms that long term TCS commonly experience and find distressing	University Cancer Center Hamburg.	N=164.	**Clinical:** 98% (N=160). Orchiectomy only – 56% (N=92). Chemotherapy at first diagnosis – 70% (N=117). Radiotherapy at any time – 23% (N=37). **Demographic:** Not reported.	Convenience	61.1%.	N/A.	Cross sectional survey.	1.	**Questionnaire:** Symptom burden: Memorial Symptom Assessment Scale (MSAS-SF).
Pallotti et al., [46] Italy.	To investigate the sexual functioning of long term TCS who underwent chemotherapy and orchiectomy	Laboratory of Seminology—Sperm Bank "Loredana Gandini".	N=241. Control N= 223.	**Clinical:** 100% chemotherapy and orchiectomy **Demographics:** Mean age at diagnosis (SD), (median) (range) - 31.3 (6.9) (31.0) (26 – 36).	Convenience	Not reported.	Not clearly reported.	Prospective longitudinal survey.	7.	**Questionnaire:** Erectile function: Index of Erectile Function 15 questionnaire (IIEF-15). **Biological data:** Subgroup of TCS underwent hormone testing of follicle stimulating hormone, luteinising hormone, testosterone.
Pühse et al., [47] Germany.	To investigate the effect of chronic pain on sexuality in TCS.	1 – University Hospital of Münster.	N=248.	**Clinical:** Chemotherapy – 45.8% (N=109). Radiation therapy – 17.2% (N=41). RPLND – 26.9% (N=64). Stage I – N=125, Stage II – N=71, Stage III – N=39 **Demographics:** Mean age at orchiectomy (SD) (range) – 35.2 (9.3) (19 – 69)	Convenience	58.2%.	N/A	Cross sectional survey.	1.	**Questionnaires:** Chronic pain: occurrence of phantom testis pain, phantom testis sensations, hallucinations. Erectile function: Abbreviated International Index of Erectile Function (IIEF-5).
Saab et al., [33] Lebanon.	To explore the experiences of Lebanese TCS.	1 - Unspecified clinic.	Not reported.	**Clinical:** Orchiectomy and chemotherapy – N=5. Orchiectomy alone – N=2. Orchiectomy and radiotherapy – N=1. **Demographic**: Mean age (range): (41 (32 – 50).	Purposive	Not reported.	N/A.	Phenomenological study.	1.	Semi-structured interview.

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Shen et al., [59] Canada.	To explore the experiences of TCS	1 - Ambulatory urologic oncology clinics at Princess Margaret Cancer Centre.	Questionnaire N=90. Focus group N=7. Phone interview N=6.	**Clinical:** Surgery only – 70.8% (N=63). Surgery/chemotherapy – 21% (N=19). Surgery/radiotherapy – 5.6% (N=5). Surgery/chemotherapy/radiotherapy – 2.2% (N=2). **Demographics:** Age (years): 18 – 50 – 90% (N=81). 51 – 60 – 8.89% (N=8). 60 + – 1.11% (N=1).	Convenience	Questionnaire 59%. Focus group 7.8%. Phone interview 6.7%.	N/A.	Mixed methods.	1.	**Questionnaires:** Demographics and treatment, Self-reported questionnaire. Survivorship knowledge: Eight questions adapted from the Breast Cancer Survivors Knowledge of Disease and Treatment Questionnaire on a five-point Likert scale. Feelings of preparedness for transition to follow-up care: 4 items from the perceived preparedness for re-entry scale. Health related distress: Modified version of the medical outcomes study-health distress scale (MOS-HDS). Continuity of care: Modified version of the Patient Continuity of Care Questionnaire (PCCQ). **Interviews:** Focus group interview, Telephone interview
Skaali et al., [48] Norway	To evaluate the cognitive functioning of TCS.	2 - Norwegian Radium Hospital and Ullevål Hospital.	N=122	**Clinical:** Surveillance/radiotherapy only **Demographic:** Age at baseline (years), median [range] – 32.5 [19-60].	Convenience	64%.	5%.	Prospective longitudinal	2.	**Neuropsychological tests:** Intellectual functioning: Norwegian version of the National Adult Reading Test (NART). Trauma: Impact of Event Scale (IES). Fatigue: The Fatigue Questionnaire. Neurotoxicity: Scale for Chemotherapy-Induced Neurotoxicity (SCIN). Neuroticism: Eysenck Personality Questionnaire. Alcohol Use: CAGE Questionnaire. Learning/memory: Hopkins Verbal Learning Test – Revised (HVLT-R). Paired associates learning test (PAL). Attention/concentration/working memory: Spatial Working Memory Test (SWM). Choice Reaction Time (CRT). Motor function: Grooved Pegboard (GP). Psychomotor speed: Trail Making Test-A (TMT-A). Colour-Word Interference Test 1 + 2 (CW-1+2). Executive Function: Colour-Word Interference Test 3 + 4 (CW 3 + 4). Trail Making Test – B (TMT-B). Word Fluency (FAS). Stockings of Cambridge (SOC). Intra-Extra Dimensional (IED) set shift.

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Skaali et al., [49] Norway	To determine the presence and frequency of self-reported cognitive issues in TCS treated with and without chemotherapy.	Not specified.	N=129 (at baseline). N=122 (at follow up.)	**Clinical:** Metastatic disease (TC Stage II -IV) – 28% (N=34). **Demographics:** Age at baseline - 32.5.	Convenience	64%.	5%.	Prospective longitudinal survey.	2.	**Semi structured interview investigating:** Self-reported cognitive problems Participants categorised their responses in either "very good" or "good" or "not so good" or "poor" in response to questions about the quality of their concentration and memory function at baseline and follow up. Concentration and memory problems before and/or after a TC diagnosis were explored and participants categorised their responses on an 11-point Likert scale. **Questionnaires:** Psychological response to TC diagnosis The Impact of Event Scale (IES). Fatigue: The Fatigue Questionnaire. Neurotoxicity: Scale for Chemotherapy-Induced Neurotoxicity (SCIN). Neuroticism: Eysenck Personality Questionnaire (EPQ-18). Alcohol use: Four-item version of the CAGE questionnaire. Intellectual functioning: Norwegian version of the National Adult Reading Test (NART). Attention, concentration and working memory: Spatial Working Memory test and the Choice Reaction Time test. Learning and memory: Hopkins Verbal Learning Test–Revised Paired. Associates Learning test. Speed of information processing: Trail Making Test Part A. Color–Word Interference Test Parts 1 and 2. Executive functions: Color–Word Interference Test Parts 3 and 4. Trail Making Test B. Word Fluency (FAS) test. Stockings of Cambridge test. Intra-Extra Dimensional Set Shift test. Motor function: Grooved Pegboard test.

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Skaali et al., [50] Norway	To determine the prevalence of cancer related distress in newly diagnosed TCP	2 - Norwegian Radium Hospital or Ulleval University Hospital.	N=135	**Clinical**: Seminoma – 53% (N=71). Non-seminoma – 47% (N=64). Stage I – 78% (N=105). Stage II – 17% (N=23). Stage III – 0% (N=0). Stage IV – 5% (N=7). **Demographic:** Mean age at diagnosis (SD) [range] – 34.8 (8.9) [19 – 60}.	Convenience	67%.	N/A.	Cross sectional survey.	1.	**Semi structured interview:** Demographics (paired relation. Employment status, previous sever somatic disease or injury, previous mental problems, sleeping problems, satisfaction with information provided by local hospital). Interviewer determined if the TCP was "well informed". **Medical records: h**istology, TC stage, time since diagnosis. **Questionnaires:** Trauma: Impact of Event Scale (IES). Anxiety and depression: Hospital Anxiety and Depression Scale. Mood affect: Positive and Negative Affect Scale (PANAS). Neuroticism: Eysenck Personality Questionnaire (EPQ). Hazardous alcohol use: The CAGE Questionnaire. Cognitive Function: Paired Associates Learning. Choice Reaction Time (CRT). Spatial Working Memory (SWM). Hopkins Verbal Learning Test Revised (HVLT-R). Grooved Pegboard. Trail Making Test A1B . Color-Word Interference Test (CW) 1–4. Word Fluency Test (FAS). Stockings of Cambridge (SOC) and/or Intra-Extra Dimensional Set Shifting (IED).
Smith et al., [18] Australia.	Explore the unmet supportive care needs of TCS.	14 – Metropolitan cancer centers (individual centers not identified).	N=224.	**Clinical:** Surveillance/surgery alone – 23% (N=55). Radiotherapy – 21% (N=52). Chemotherapy – 37% (N=90). **Demographics:** Not reported	Convenience	70% of contact able. 50% of eligible.	N/A.	Cross sectional survey.	1.	**Questionnaires:** Unmet supportive care needs: Cancer Survivors' Unmet Needs (CaSUN). Psychological distress: Depression Anxiety Stress Scales short-form (DASS21). Health related quality of life: SF-36v2.
Smith et al., [23] Australia.	Determine the frequency and severity at which TCS experience psychological distress and health-related quality of life and identify correlates.	14 - Metropolitan cancer centers (individual centers not identified).	N=244.	**Clinical:** Surveillance/surgery alone – 23% (N=55). Radiotherapy – 21% (N=52). Chemotherapy – 37% (N=90). Chemotherapy + radiotherapy + further surgery – 19% (N=45) (RPLND – 67% (N= value not reported)). **Demographics:** Not reported	Convenience	70% of contact able. 50% of eligible.	N/A.	Cross sectional survey.	1.	**Questionnaires:** Psychological distress: Depression Anxiety Stress Scales-Short Form (DASS21). Generic Health Related Quality of Life: SF-36v2. Testicular Cancer Health Related Quality of Life European Organization for Research and Treatment of Cancer (EORTC) TC module QLQ-TC26.Coping style: Mental Adjustment to Cancer Scale (MAC). Unmet supportive care needs: Cancer Survivors' Unmet Needs measure (CaSUN).

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Soleimani et al., [51] Canada.	To identify the psychosocial needs of individuals with germ cell tumours	1 - B. C Cancer.	N=349.	**Clinical:** Pure seminoma: 55.9% (N=195). Mixed germ cell tumour: 22.1% (N=77). Other: 22.1% (N=77). **Demographics:** Median age (years) – 33.	Convenience	Not reported.	N/A.	Cross sectional survey.	1.	Psychological distress PsychoSocial Screen for CANcer. Other domains Revised (PSSCAN-R) and the Canadian Problem Checklist (CPC).
Stouten-Kemperman et al., [52] Netherlands	To determine the effects of chemotherapy on the brains and cognitive functioning of TCS.	1 - Netherlands Cancer Institute.	N=45.	**Clinical:** Chemotherapy/ surgery only **Demographic:** Mean age (SD): 43.1 (7.5)/48.2 (9.5).	Convenience	55%.	N/A.	Casual comparative	1.	**Neurocognitive tests** Executive function: Controlled Oral Word Association Test Word Fluency, Trail Making Test card B, Tower of London, Mental rotation Task. Visual memory: Visual Reproduction Test of the Wechsler Memory Scale-Revised. Verbal memory: Dutch version of the California Verbal Learning Test. Motor speed: Finger-tapping. Processing speed: Digit Symbol-Coding Test of the WAIS-III. Trail Making Test card A. Attention: Eriksen Flanker Task. Digit Span of the WAIS-III **Questionnaires:** Quality of Life: European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-C30 (QLQ-C30). Perceived stress: Perceived Stress Scale. Trauma: Trauma Screening Questionnaire: Cognitive complaints: Cognitive Functioning Scale- Revised of the Medical Outcomes Study. Impact of Cancer: Impact of Cancer scale version 2 (IOCv2). Expectations of sterotyping: Stereotype vulnerability questionnaire. Perceived capability to work: Workability questionnaire. **General health:** Abdominal circumference. Systolic and diastolic blood pressure, **Brain imaging:** MRI
Tasdemir et al., [53] Turkey.	To determine the presence of sexual dysfunction, depression, anxiety, and gonadotropin hormone levels in TCS treated with chemotherapy.	Department of Medical Oncology and Urology, Inonu University Firat University.	N=27. Control size unknown.	**Clinical:** Not reported. **Demographics:** Mean age (SD) - 34 years (8.9).	Convenience	Not reported.	N/A.	Cross sectional survey.	1.	Depressive symptoms: Beck depression inventory-II (BDI-II) 22. Anxiety symptoms: Beck Anxiety Scale. Sexual Function: International Index of Erectile Function (IIEF-15). Blood samples: Serum Luteinizing Hormone. Follicle stimulating hormone. Testosterone.

Table 2 (continued)

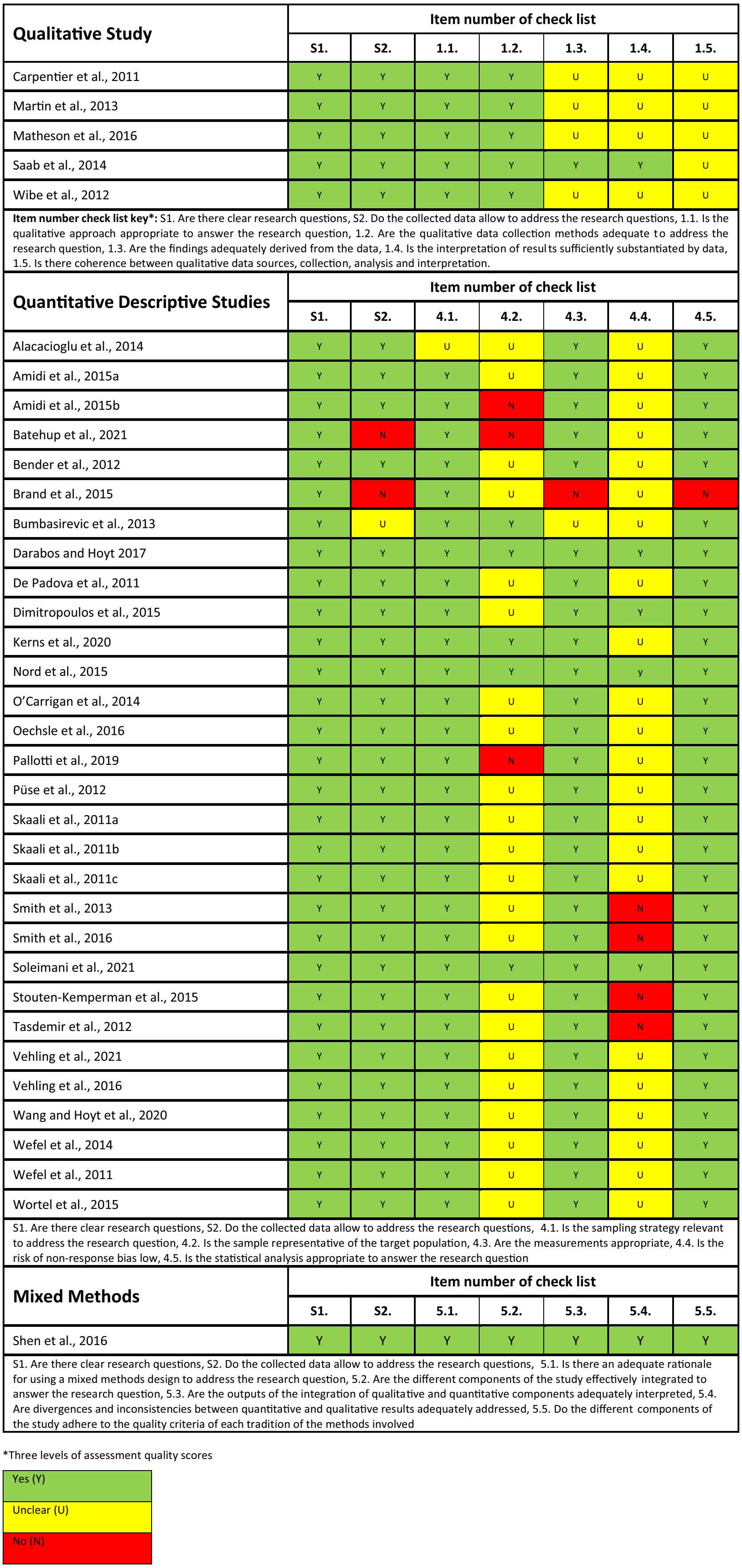
Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Vehling et al., [54] Germany.	Explore TCS experience of positive and negative life changes after cancer	Uro-oncological outpatient ward, University Medical Center, the University Cancer Center Hamburg. Private practice, Hamburg, Germany.	N=164.	**Clinical:** Chemotherapy - 76% (N=124). Surgery – 98% (N=160). Radiotherapy – 23% (N=38). **Demographics:** Mean age (SD, range) – 44.4 (9.6, 24-77)	Convenience	61.1%.	N/A.	Cross sectional survey.	1.	Perceived positive and negative life changes: Modified Posttraumatic Growth Inventory (PTGI). Depression: Patient Health Questionnaire-9 (PHQ-9). Anxiety: Generalized Anxiety Disorder Screener-7 (GAD-7). Symptom burden: Memorial Symptom Assessment Scale—Short Form (MSAS-SF).
Vehling et al., [55] (same study as above) Germany.	Investigate and establish the presence of anxiety and depression in TCS and analyse the influence of correlates.	Uro-oncological outpatient ward, University Medical Center, University Cancer Center Hamburg . Private practice in Hamburg (no further detail supplied).	N=164.	**Clinical**: None – 2% (N=4). Orchiectomy only – 56% (N=92). Surgery more than orchiectomy – 42% (N=68). **Demographics:** Mean age (SD) – 44.4 (9.6).	Convenience	61.1%.	N/A.	Cross sectional study.	1.	Sociodemographic data: Unspecified 'standardised self-report questionnaire'. Anxiety: Generalized Anxiety Disorder Screener-7 (GAD-7). Depression: Patient Health Questionnaire-9 (PHQ-9). Physical symptoms: The Memorial Symptom Assessment Scale – Short Form.
Wang and Hoyt, [24] USA.	To explore the relationship between benefit finding and psychological adjustment in TCS	Number unspecified. Men enrolled in the California Cancer Registry.	N=171.	**Clinical:** Surgery and chemotherapy. I – 35% (N= value not reported). II or III – 65% (N= value not reported). **Demographics:** Mean age (SD) – 25.2 (3.3).	Convenience	Not reported.	N/A.	Cross sectional survey.	1.	**Questionnaires:** Benefit from testicular cancer: The Benefit Finding Scale (BFS). Threat to masculinity: Cancer-related Masculine Threat Scale. Psychological Adjustment to cancer: The Positive and Negative Affect Schedule (PANAS). The Center for Epidemiologic Studies Depression Scale (CES-D). Self-esteem: Rosenberg Self-Esteem Scale.
Wefel et al., [56] USA.	To investigate the influence of chemotherapy treatment on cognitive functioning in TCS	Genito-urinary medical service of MD Anderson Cancer Centre, Houston, Texas.	N=69.	**Clinical:** all treated by chemotherapy. Stage I – 92.9% (N=13) Stage II – 7.1% (N=1) Stage III – 0% (N=0) **Demographics:** Mean age (SD) [range] - 31.0 (±7.5) [18.5 – 50.7].	Convenience	Not reported.	Unclear	Prospective longitudinal.	3.	**Neuropsychological tests:** Attention: WAIS-R Digit Span Psychomotor speed: WAIS-R Digit Symbol. Trail Making Test Part A. Language: MAE Controlled Oral Word Association. Learning and memory: HVLT Trials 1-3, Total Recall. Executive function: Trail Making Test B. Motor: Grooved Pegboard (dominant hand). Grooved pegboard (nondominant hand) **Questionnaires:** Depression: Centre for Epidemiologic Studies Depression Scale. Anxiety: State-Trait Anxiety Inventory – State score **Biological data:** Human chorionic gonadotropin. Alpha fetoprotein. Testosterone. Lactate dehydronase

Table 2 (continued)

Author and Year Country	Purpose	Setting	Sample size	Participants	Sampling	Response rate	Attrition	Design	Time points	Data collection tools
Wefel et al., [57] (same study as above) USA.	To investigate the prevalence of cognitive impairment in TCS prior to the administration of adjuvant therapies.	Genito-urinary medical service of MD Anderson Cancer Centre, Houston, Texas.	N=69.	**Clinical:** Orchiectomy – 100%. I – 51% (N=35) II- 33% (N=23) III – 15% (N=10) **Demographic:** Mean age (SD) [range] - 31.0 (±7.5) [18.5 – 50.7].	Convenience	Not reported.	N/A.	Cross sectional.	1.	**Neuropsychological tests:** Attention: WAIS-R Digit Span. Psychomotor speed: WAIS-R Digit Symbol. Trail Making Test Part A. Language: MAE Controlled Oral Word Association. Learning and memory: HVLT Trials 1-3, Total Recall. Executive function: Trail Making Test B. Motor: Grooved Pegboard (dominant hand). Grooved pegboard (nondominant hand) **Questionnaires:** Depression: Centre for Epidemiologic Studies Depression Scale. Anxiety: State-Trait Anxiety Inventory – State score **Biological data:** Human chorionic gonadotropin. Alpha fetoprotein. Testosterone. Lactate dehydronase
Wibe et al., [34] Norway.	Determine If online patient nurse communication service meets patient needs and how patients utilised the service	Cancer department, Tertiary Hospital. (Hospital not specified).	Messages N=54. From 12 patients. 5 Interviews from 5 individuals included in study.	**Clinical:** Diagnosed with testicular cancer in the last three months and were undergoing treatment at the tertiary hospital – (100%). **Demographics:** Age (range): 24 – 51 years. Mean age: 37. Median age: 36.	Convenience	41.6% (for interviews).	N/A.	Phenomenological study.	1.	Semi-structured Interviews. Data from online patient-nurse communication.
Wortel et al., [58] Netherlands	To determine the effect of Radiotherapy and Orchiectomy on the sexual functioning and body image of TCP.	1 – Department of Radiation Oncology. Further details not reported.	N=120.	**Clinical:** combination therapies. pT1 – 114 (71). pT2 – 47 (29). N0 – 145 (90). N1 – 14 (9). N2 – 2 (1). **Demographic:** Median age at treatment (range): 36 (18-70).	Convenience	68%.	25%	Prospective longitudinal.	3.	**Questionnaire:** Dutch translation of sexual function questionnaire.

Cognitive Impairment (CI); testicular cancer (TC); testicular cancer patient (TCP); testicular cancer survivor (TCS); bilateral testicular cancer (BTC); contralateral germ cell neoplasia (GCNIS); quality of life (QoL); unilateral testicular cancer (UTC); contralateral germ cell neoplasia in situ (cGCNIS); retroperitoneal lymph node dissection (RPLND); Brief Male Sexual Function Inventory for Urology (BMSFIU); Leisure time physical activity; three cycles of bleomycin, etoposide, and cisplatin (BEPX3); four cycles of etoposide and cisplatin (EPX4); 4 cycles of bleomycin, etoposide and cisplatin (BEPX4); 4 cycles of etoposide, ifosfamide, and cisplatin (VIPX4); 5 cycles of etoposide, ifosfamide, and cisplatin (VIPX5); week (wk); metabolic equivalent of task (METs); International Germ Cell Cancer Collaborative Group (IGCCCG); bleomycin, etoposide and cisplatin (BEP); testicular cancer survivor (TCS); fear of recurrence (FoR); Beck Depression Index (BDI); benefit finding (BF); pT1; pT2;N0; N1; N2; scale for chemotherapy induced long term neurotoxicity (SCIN); NART; bleomycin, etoposide, cisplatin (BEP); post chemotherapy retroperitoneal lymph node dissection (PC-RPLND); interquartile range (IQR); low limit of normal (LLN); upper limit of normal (ULN); follicle stimulating hormone (FSH); luteinizing hormone (LH); hospital depression and anxiety scale (HADS)

Table 3 Quality appraisal of primary studies



Qualitative Study	Item number of check list						
	S1.	S2.	1.1.	1.2.	1.3.	1.4.	1.5.
Carpentier et al., 2011	Y	Y	Y	Y	U	U	U
Martin et al., 2013	Y	Y	Y	Y	U	U	U
Matheson et al., 2016	Y	Y	Y	Y	U	U	U
Saab et al., 2014	Y	Y	Y	Y	Y	Y	U
Wibe et al., 2012	Y	Y	Y	Y	U	U	U

Item number check list key*: S1. Are there clear research questions, S2. Do the collected data allow to address the research questions, 1.1. Is the qualitative approach appropriate to answer the research question, 1.2. Are the qualitative data collection methods adequate to address the research question, 1.3. Are the findings adequately derived from the data, 1.4. Is the interpretation of results sufficiently substantiated by data, 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation.

Quantitative Descriptive Studies	Item number of check list						
	S1.	S2.	4.1.	4.2.	4.3.	4.4.	4.5.
Alacacioglu et al., 2014	Y	Y	U	U	Y	U	Y
Amidi et al., 2015a	Y	Y	Y	U	Y	U	Y
Amidi et al., 2015b	Y	Y	Y	N	Y	U	Y
Batehup et al., 2021	Y	N	Y	N	Y	U	Y
Bender et al., 2012	Y	Y	Y	U	Y	U	Y
Brand et al., 2015	Y	N	Y	U	N	U	N
Bumbasirevic et al., 2013	Y	U	Y	Y	U	U	Y
Darabos and Hoyt 2017	Y	Y	Y	Y	Y	Y	Y
De Padova et al., 2011	Y	Y	Y	U	Y	U	Y
Dimitropoulos et al., 2015	Y	Y	Y	U	Y	Y	Y
Kerns et al., 2020	Y	Y	Y	Y	Y	U	Y
Nord et al., 2015	Y	Y	Y	Y	Y	y	Y
O'Carrigan et al., 2014	Y	Y	Y	U	Y	U	Y
Oechsle et al., 2016	Y	Y	Y	U	Y	U	Y
Pallotti et al., 2019	Y	Y	Y	N	Y	U	Y
Püse et al., 2012	Y	Y	Y	U	Y	U	Y
Skaali et al., 2011a	Y	Y	Y	U	Y	U	Y
Skaali et al., 2011b	Y	Y	Y	U	Y	U	Y
Skaali et al., 2011c	Y	Y	Y	U	Y	U	Y
Smith et al., 2013	Y	Y	Y	U	Y	N	Y
Smith et al., 2016	Y	Y	Y	U	Y	N	Y
Soleimani et al., 2021	Y	Y	Y	Y	Y	Y	Y
Stouten-Kemperman et al., 2015	Y	Y	Y	U	Y	N	Y
Tasdemir et al., 2012	Y	Y	Y	U	Y	N	Y
Vehling et al., 2021	Y	Y	Y	U	Y	U	Y
Vehling et al., 2016	Y	Y	Y	U	Y	U	Y
Wang and Hoyt et al., 2020	Y	Y	Y	U	Y	U	Y
Wefel et al., 2014	Y	Y	Y	U	Y	U	Y
Wefel et al., 2011	Y	Y	Y	U	Y	U	Y
Wortel et al., 2015	Y	Y	Y	U	Y	U	Y

S1. Are there clear research questions, S2. Do the collected data allow to address the research questions, 4.1. Is the sampling strategy relevant to address the research question, 4.2. Is the sample representative of the target population, 4.3. Are the measurements appropriate, 4.4. Is the risk of non-response bias low, 4.5. Is the statistical analysis appropriate to answer the research question

Mixed Methods	Item number of check list						
	S1.	S2.	5.1.	5.2.	5.3.	5.4.	5.5.
Shen et al., 2016	Y	Y	Y	Y	Y	Y	Y

S1. Are there clear research questions, S2. Do the collected data allow to address the research questions, 5.1. Is there an adequate rationale for using a mixed methods design to address the research question, 5.2. Are the different components of the study effectively integrated to answer the research question, 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted, 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed, 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved

*Three levels of assessment quality scores

🟩 Yes (Y)
🟨 Unclear (U)
🟥 No (N)

Table 4 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
Alacacioglu et al., 2014 [22]	✓	✓	-	-	-	-	-	✓	-	-	-	3
Amidi et al., 2015a [35]	-	✓	✓	-	-	-	-	-	-	-	-	2
Amidi et al., 2015b [36]	-	✓	✓	-	-	-	-	-	-	-	-	2
Batehup et al., 2021 [37]	-	✓	-	✓	✓	-	-	✓	-	✓	✓	6
Bender et al., 2012 [15]	✓	✓	-	-	✓	-	-	✓	✓	-	✓	6
Brand et al., 2015 [38]	✓	✓	-	-	✓	-	-	✓	-	✓	-	4
Bumbasirevic et al., 2013 [39]	✓	✓	-	-	-	-	-	✓	-	-	-	3
Carpentier et al., 2011 [31]	-	✓	-	-	-	-	-	✓	-	-	✓	3
Darabos and Hoyt, 2017 [40]	-	✓	-	-	-	-	-	-	-	-	-	1
DePadova et al., 2011 [41]	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	8
Dimitropoulos et al., 2016 [42]	-	-	-	-	-	-	-	✓	-	-	-	1
Kerns et al., 2020 [43]	✓	✓	-	-	-	-	-	✓	✓	-	-	4
Martin et al., 2013 [21]	-	-	-	-	✓	-	-	-	-	-	-	1
Matherson et al., 2016	✓	✓	-	-	✓	-	-	✓	-	-	✓	5
Nord et al., 2015 [44]	-	-	-	-	-	-	-	-	✓	✓	-	1
O'Carrigan et al., 2014 [45]	✓	✓	-	-	-	-	-	-	-	-	-	2
Oechsle et al., 2016 [20]	✓	✓	✓	-	-	-	-	✓	-	-	-	4
Pallotti et al., 2019 [46]	✓	-	-	-	-	-	-	✓	-	-	-	2
Pühse et al., 2012 [47]	✓	-	-	-	-	-	-	✓	-	-	-	2
Saab et al., 2014 [33]	-	✓	-	-	-	-	-	✓	-	-	-	2

Table 4 (continued)

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
Shen et al., 2016 [59]	-	✓	-	✓	✓	-	-	-	-	-	-	3
Skaali et al., 2011a [48]	-	-	✓	-	-	-	-	-	-	-	-	1
Skaali et al., 2011b [49]	✓	-	✓	-	-	-	-	-	-	-	-	2
Skaali et al., 2011c [50]	-	✓	✓	-	-	-	-	-	-	-	-	2
Smith et al., 2013 [18]	-	✓	-	✓	✓	-	-	✓	✓	-	✓	6
Smith et al., 2016 [23]	✓	✓	-	-	-	-	-	✓	-	-	✓	4
Soleimani et al., 2021 [51]	✓	✓	-	-	✓	✓	-	-	✓	✓	-	6
Stouten-Kemperman et al., 2015 [52]	✓	✓	✓	-	-	-	-	-	✓	-	-	4
Tasdemir et al., 2012 [53]	-	✓	-	-	-	-	-	✓	-	-	-	2
Vehling et al., 2021 [54]	✓	✓	-	-	-	-	-	-	-	-	-	2
Vehling et al., 2016 [55]	✓	✓	-	-	-	-	-	-	-	-	-	2
Wang and Hoyt, 2020 [24]	-	✓	-	-	-	-	-	-	-	-	-	1
Wefel et al., 2014 [56]	-	-	✓	-	-	-	-	-	-	-	-	1
Wefel et al., 2011 [57]	-	✓	✓	-	-	-	-	-	-	-	-	2
Wibe et al., 2012 [34]	-	-	-	-	✓	-	-	✓	-	-	-	2
Wortel et al., 2015 [58]	✓	✓	-	-	✓	-	-	✓	-	-	-	4
Number of domains explored across all studies	18	26	9	4	11	1	0	19	4	4	7	

> whatever, it was just falling off. That was probably as devastating as anything, for me. It was just like, 'wow' (Participant 1)" (page 742) [31].

Other less commonly experience symptoms but still caused distress among testicular cancer survivors included itching, cough, sweats, shortness of breath, dizziness, skin changes, mucositis, numbness and tingling, feeling bloated, changed taste, urination difficulties, diarrhoea, and constipation [20]. Additionally, there were problems with fertility [23, 38, 41, 58], hypogonadism [43, 45, 46], higher white matter hyperintensities and radial kurtosis [52], and low testosterone [38] were reported. Chemotherapy-induced consequences such as obesity, peripheral sensory neuropathy, renal disease, tinnitus, hearing loss, Raynaud phenomenon, and autonomic neuropathy were frequently experienced. However, long-term conditions such as hypertension, thromboembolism, hypocholesteraemia, peripheral artery disease, diabetes, thyroid disease, coronary artery disease, transient ischaemic attack, and stroke were identified less frequently in this young population [43]. Testicular cancer survivors were found to have lower mean vitality, physical functioning, physical role functioning, and general health when compared to the general healthy population [23]. Men had physical concerns related to having one testicle which was intertwined with psychological consequences and intimacy concerns [38]. Noteworthy, 20% of the participants who received a prothesis were unhappy with the aesthetic result [18].

Interpersonal/intimacy needs

Individuals affected by testicular cancer reported needing help with their sex life [18, 37] because they were embarrassed to discuss this with healthcare professionals [38]. Only 14% of testicular cancer survivors reported having "none/a little" issues in their sex life [41]. Some men reported a decreased level of sexual function post-treatment and long-lasting into survivorship [39]. The most commonly experienced issues for these young men included erectile dysfunction [39, 43, 46, 47, 53], reduced erectile rigidity [58], and inability to maintain an erection during intercourse due to chronic pain [47]. Other concerns were reduced sexual interest [20, 23, 59], lack of sexual desire [39, 46, 47], and in frequent of sexual activity [22, 47, 58]. Disorders of ejaculation were prevalent [39, 42, 47] with loss of antegrade ejaculation [42]. Decreased sexual satisfaction [47], enjoyment of intercourse [42], intercourse satisfaction [46], reduced pleasure [58], decreased orgasm frequency [42], and decreased orgasm intensity [47] were also reported. Problems within intimate relationships also surfaced because some participants felt they could not speak to their partner about sexual issues [23], which reported decreased general satisfaction [46] or decreased satisfaction with their sexual life and relationship [42]. For other young men, they reported concerns about finding a future partner [38] and did not know how to communicate to discuss this sensitive issue with partners or healthcare professionals [22]. Treatments including chemotherapy and extended lymph node dissection were associated with poor sexual functioning [42, 43].

> "Sexual questions for example, which might have come up during the doctors' rounds … This might be easier to ask about in an e-mail to a person that you don't know than when the doctor asks: "What about your … (sexual function)?" Then you answer: "Oh, that's OK" or "That's normal" or whatever …" (page 4) [34].

Health system/information needs

Some studies identified that men wanted improved communication in the healthcare system to address problems with co-ordination of their care [23, 37]. However, participants also needed informational support to provide reassurance that they were receiving the best care [23, 37] and that their complaints were being addressed in a timely manner. Informational supports within the healthcare system were, at times, inadequate for patients [15, 59] and their partners [59] and omitted recovery expectation post-treatment [15, 59] to inform rehabilitation care plans.

> "There was no discussion that I remember that was any, you know, 'if you're feeling like this, then come and talk to us,' or, you know, 'there's counselling available,' or anything like that. I don't recall anything like that for the psychological side of any concerns, really." (page 16) [59].

It was important that men received understandable and up-to-date information to support decision-making [37] at diagnosis and treatment phases [51]. Fundamental gaps in information provision were observed for knowledge and understanding of which treatments men received, and associated risks of treatments, lifestyle advice to support self-management within the multidisciplinary team, and timely access to results, and how to self-report concerning symptoms to healthcare professionals [59]. Patients also identified that websites were critical for accessing information [41] but raised questions about the quality of information which is being accessed by men.

Men reported informational needs related to deciding on which prothesis to proceed with [15], and 44% of patients did not receive any information related to the option of a prothesis [58]. Men also wanted information in relation to how to access to complementary or alternative therapies [15] and information in relation to sexual recovery [38]. Noteworthy, 50% of testicular cancer survivors did not know what information supports were available to them [59].

Cognitive needs

Testicular cancer survivors frequently experienced cognitive impairment [20, 35, 36, 48–50, 52, 56, 57] or cognitive decline over time [48, 56] post-treatment and into survivorship. Participants self-reported cognitive difficulties [20, 50, 52], but were not always reflected in objective neuropsychological testing used to evaluate cognitive decline [49]. One study [20] found that of the 32% of participants who reported difficulty concentrating, 8% of the participants found it highly distressing. None of the participants across these studies reported receiving timely intervention or support for their difficulties with cognition. Evidence identified that as many as 58% of testicular cancer survivors can experience cognitive impairment [35, 36] which is significant given this young cohort of men who could be either studying or working in paid employment. One study [49] found that self-reported cognitive impairment was associated with psychological distress.

> ‘It just feels kind of like you’re incomplete. Just as a person you feel like you’re missing something you’re supposed to have. I guess it’s just the fact that it doesn’t have any real effect but there’s still something missing. So it’s just that weird dichotomy’ (Participant 9)” (page 742) [31].

Social needs

Men diagnosed with testicular cancer reported the need to talk to other survivors [15, 23, 37]. Other social needs included how to navigate sensitive conversations of their cancer diagnosis in the work environment [15, 37]. Testicular cancer survivors and their caregivers indicated that cancer made their social relationships difficult [41] and they wanted help and advice in how to create new relationships with intimate partners [37]. Testicular cancer survivors needed help knowing how to deal with this impact on relationships [37] and were found to have lower social functioning than healthy populations [23].

> “‘I just think it just helped just reassure me, like I wasn’t a nutter, or some weirdo, and you’re not the only person, you won’t ever be the only person who’s gone through it’ (P20, T1, 22 years., single, surgery and chemotherapy)” (page 199) [32].

Family-related needs

Young men expressed needs in knowing how to support their partners or families [37], how to communicate with their young children [38], and concerns about being unable to have children due to fertility issues [38]. It was common for men to experience issues within their existing relationships which caused emotional strain [41, 51].

> “An infertile man … the way people perceive him makes him want to beat himself … I suffered … a man is about sex and kids to a certain extent.” (page 206) [33].

Practical needs

Practical unmet needs included a lack of assistance to access government benefits [15, 23], guidance on life insurance, and accessible parking at the hospital [23]. Testicular cancer survivors reported having difficulties with their work or study [41], experienced higher unemployment than general populations [43], with an increased risk of loss of employment [44]. One study [52] highlighted that upon testicular cancer survivors return to work, some required changes to their workplace to return to work, and others did not return to their previous role because of cognitive impairment [52].

> “I don’t know what to look for, I don’t know what to expect.” (page e16)[59].

Patient-clinician communication needs

These were some important implications for patient-clinician communication needs identified across four studies [18, 37, 41, 59]. Men expressed that they wanted to feel more supported in the self-management of their health in partnership with their healthcare team [23, 37].

> “There was no discussion that I remember that was any, you know, ‘if you're feeling like this, then come and talk to us,’ or, you know, ‘there's counselling available,’ or anything like that. I don't recall anything like that for the psychological side of any concerns, really. The attitude seemed to be, if something bothers you, tell us and we'll deal with it. We're not going to tell you in advance what any of those things might be.” (page e16) [59].

However, on the whole, men expressed satisfaction and confidence with their patient-clinician communication needs [59].

Spiritual needs

Only two studies [37, 51] explored the spiritual needs in this patient group. One study [51] identified that faith and the meaning of life were rated as least concerning unmet needs [43] and testicular cancer survivors reported that they had no unmet spiritual needs [37] in this young patient group.

Daily living needs

Across all the studies, no information was reported in relation to daily living unmet needs of individuals affected by testicular cancer.

Discussion

This systematic review sets out to identify the unmet supportive care needs among young men diagnosed with testicular cancer. The included studies identified that needs varied in terms of distress and frequency across different domains of supportive care. The current review found emotional, intimacy, and physical needs to be the most frequently reported unmet domains of care. This is a similar outcome to reviews conducted in other cancer populations [7–9, 12]. However, cognitive needs of individuals affected by testicular cancer were problematic for these young men, compared to mainstay experiences of unmet needs in other cancer groups [7–9, 12]. Cognitive impacts were investigated at varying time points from immediately post-orchiectomy [35, 48–50, 56, 57] and into survivorship [20, 35, 52]. Cognition was found to be negatively impacted by orchiectomy alone [35, 57]. However, evidence about the relationship with chemotherapy on cognitive function [49, 52, 56] or indeed lack of association [35, 48] is conflicting. Amidi [35] found that cortisol levels were associated with impaired cognitive function, while increased C-reactive protein was associated with poor verbal fluency test outcomes. Furthermore, self-reported cognitive problems were correlated to Raynaud-like symptoms and fatigue [49], and cognitive decline was also associated with hearing loss [48]. Self-reported measures of cognitive impairment have also been linked to emotional/psychological needs [49, 50]. Therefore, it should be noted that self-reported cognitive issues, and objective measurable cognitive impairment in testicular cancer survivors is conflicting [49] which is consistent within the literature in other cancer populations [60]. Furthermore, a meta-analysis [61] of the effects of chemotherapy on cognition in patients with cancer remains unclear. Given the findings from this current review, future studies should explore mechanism pathways for both objective, and subjective measures in relation to cognitive impairment in this patient group. Gaining this information will help to leverage the development of interventions for cognitive pre -and/or rehabilitation.

This review found hypogonadism to occur in testicular cancer survivors. Hypogonadism is known to result in low testosterone in the male sex [62]. Low testosterone has been associated with worse sexual functioning [63]. This review identified that hypogonadism was reported, and one study found that it was not related to sexual functioning [46]. It is established that sexual dysfunction can be of psychogenic nature [63] and the findings of this review support that this may be true for some testicular cancer survivors. One study [58] found that in men who received a prothesis they reported no sexual dysfunction, whereas men who did not have a prothesis did self-report issues with sexual dysfunction. Body image concerns have been found to be associated with sexual dysfunction in testicular cancer survivors [64]. Intimacy needs are high in patient populations where the cancer affects the reproductive organs or secondary sexual characteristics [65] which can negatively impact the sexuality of the affected person. However, it is unlikely all sexual dysfunction reported in this review is only attributed to a psychogenic nature given the consistently high rates of sexual dysfunction in the testicular cancer survivor populations [66]. Other issues encountered by these men were a lack of opportunity to discuss these problems with their intimate partner or healthcare professions, often because of embarrassment. Therefore, healthcare professionals should be mindful of these concerns and tactfully and sensitively explore concerns to ensure that men receive timely intervention.

Health system/information needs were frequently unmet. Reasons for these gaps were not explored in the included studies but would be an important clinical focus for future research. The spiritual needs of testicular cancer survivors were rarely discussed, and one study [37] found that testicular cancer survivors did not report any unmet spiritual needs. It is unclear to determine the spiritual needs of individuals affected by testicular cancer because of the lack of data. It is also noteworthy that the men represented in this systematic review also did not express concerns with existential issues, or fear of death and dying, concerns commonly experienced in other cancer populations [7–9, 12]. It would be important to explore whether these were concealed concerns because of their age or reticence to disclose, but ultimately this remains unknown. Likewise, there were no identified daily living needs which might be explained in part because of the young age demographic, but men did share challenges about their practical needs.

Testicular cancer survivors were found to experience greater work loss and take more sick leave than the general population [44]. Unemployment rates for testicular cancer survivors were also higher than the general population

[43]. Furthermore, peripheral neuropathy was associated with unemployment and disability leave [43], and receiving four or more courses of chemotherapy was associated with work loss [44]. There are practical needs which have also been identified in the wider cancer care literature [67, 68]. However, specific to this young population were concerns about work, school, and finances compared to older patients [51]. This is logical as this population is still generally establishing a career and financial independence [69]. Family-related needs were infrequently investigated in the literature. The family needs of individuals affected by testicular cancer should be a central focus for future research, particularly given the impact on intimacy and relationships.

Lastly, future directions for research should focus on developing a core outcome set (COS) for testicular cancer survivorship research. This review has identified significant heterogeneity of study outcomes and in particular patient reported outcomes measures (PROMs). There were a total of 57 different PROMs used across the studies in this systematic review and a range of diverse methods used.

Limitations

This systematic review has many strengths including the clear and specific methodology which followed a registered priori protocol. In addition, to the independent reviewer's contributions throughout the entirety of the systematic review process, the study provided insights across heterogenous study populations in terms experiences of unmet supportive care needs. 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. The review only included articles in the English language, and as such, it may limit our understanding of the area globally considering cultural and societal differences. The review also did not include any participants from low- to middle-income countries, and efforts/funding should be targeted to support cancer care in developing nations as a future priority. Lastly, this review only included studies published in the English language, and therefore by omission, valuable insights may have been missed.

Conclusion and implications for cancer survivors

The interrelated nature of the unmet supportive care needs experienced by individuals affected by testicular cancer emphasises the importance of holistic, person-centred approaches to care delivery. The contemporary evidence identified in this review highlights areas of clinical practice that require improvement to enhance the healthcare experiences of individuals affected by testicular cancer.

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Declarations

Conflict of interest The authors declare no competing interests.

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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.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
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.	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=292072
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.	4 and 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 Table 2

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).	5-6
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.	6
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).	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.	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.	Figure 1

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.	7
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).	Table 2
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.	Table 3, 4, supplementary table 2
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	7-12
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Table 3
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).	12-15
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).	15
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	15
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.	N/A

Supplementary Table 2 - Record of database searches

Database: APA PsycINFO			
Date of Search: 17/11/2021			
Symbols used in this document:			
“ ” finds a phrase			
Asterisk (*) = truncates stem of a word			
Search #	**Concept/Explanation**	**Search Terms/Strategy**	**# of Results**
#1	“Population” – individuals affected by testicular cancer	"Testicular Neoplasm*" OR "testicular cancer*"	320
#2	“Outcomes of interest”	"unmet supportive care needs" OR "patient needs" OR "care needs" OR "family needs" OR "caregiver needs" OR "supportive care" OR "supportive care needs" OR "health system" OR "health information" OR "patient-clinician communication" OR "patient care team" OR "multidisciplinary care team" OR "patient care needs" OR "patient comfort" 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 "continuity of patient care and oncology and palliative and primary care" OR "continuity of patient care" OR "respite care" OR "social support" OR "social relationships" OR "support" OR "financial support" OR "nutritional support" OR "decision support techniques" OR "subacute care" OR "ambulatory care" OR "outpatients" OR "primary health care" OR "acute care" OR "inpatients" OR "hospital care" OR "health planning support" OR "behavioural symptoms" OR "symptom assessment" OR "symptom management" OR "urinary symptoms" OR "signs and symptoms" OR "symptom distress" OR "symptoms" OR "sexual dysfunction" OR "sexual health" OR "information literacy" OR "information needs" OR "needs	1,451,825

		assessment" OR "spiritual therapies" OR "spirituality" OR "religion" OR "faith" OR "belied system" OR "spiritual needs" OR "hospice and palliative care nursing" OR "palliative care" OR "pain" OR "pain management" or "pain measurement" OR "human needs" OR "physical needs" OR "emotional support" OR "emotional needs" OR "family support" OR "family involvement" OR "family engagement" OR "family needs" OR "social needs" OR "interpersonal relations" OR "interpersonal" OR "activities of daily living" OR "daily living needs" OR "bereavement" OR "grief" OR "loss"	
#3	“Outcome of interest and individuals affected by testicular cancer”	1 AND 2 Limiters – English language and Peer Reviewed	138

Database: Cumulative Index to Nursing and Allied Health Literature (CINAHL)			
Date of Search: 17/11/2021			
Symbols used in this document:			
MH = Main Heading or “CINAHL Heading”			
“ ” finds a phrase			
Asterisk (*) = truncates stem of a word			
Search #	**Concept/Explanation**	**Search Terms/Strategy**	**# of Results**
#1	“Population” – individuals affected by testicular cancer	(MH "Testicular Neoplasms") OR “testicular cancer*” OR “testicular neoplasm*”	3,537
#2	“Outcomes of interest”	"unmet supportive care needs" OR "patient needs" OR "care needs" OR "family needs" OR "caregiver needs" OR "supportive care" OR “health system” OR (MH “health information”) OR "patient-clinician communication" OR “patient care team” OR (MH "Multidisciplinary Care Team”) OR “patient care needs” OR “patient comfort” OR “patient care planning” OR “patient care bundles” OR (MH "Patient Care") OR (MH "Patient Centered Care") OR “person centered care”	767,048

		OR (MH "Family Centered Care") OR (MH "Progressive Patient Care") OR "continuity of patient care and oncology and palliative and primary care" OR (MH "Continuity of Patient Care") OR (MH "Respite Care") OR “social support” OR (MH "Support, Psychosocial") OR “social relationships” OR (MH "Financial Support") OR (MH "Nutritional Support") OR (MH "Decision Support Techniques") OR (MH "Subacute Care") OR (MH "Ambulatory Care") OR (MH "Outpatients") OR (MH "Primary Health Care") OR (MH "Acute Care") OR (MH "Inpatients") OR “hospital care” OR “health planning support” OR (MH "Behavioral Symptoms") OR “symptom assessment” OR “symptom management” OR “urinary symptoms” OR (MH "Signs and Symptoms") OR "Signs and Symptoms" OR (MH "Signs and Symptoms, Digestive") OR (MH "Symptom Distress") OR (MH "Symptoms") OR (MH "Sexual and Gender Disorders") OR “sexual dysfunction” OR (MH "Sexual Health") OR (MH "Information Literacy") OR "Information Literacy" OR (MH "Information Needs") OR “information needs” OR (MH "Needs Assessment") OR "spiritual therapies" OR (MH "Spirituality") OR (MH "Religion and Religions") OR "faith" OR “belief system” OR “spiritual needs” OR (MH "Hospice and Palliative Nursing") OR (MH "Palliative Care") OR (MH "Pain") OR (MH "Pain Measurement") OR (MH "Pain Management") OR (MH "Human Needs (Physiology) OR “physical needs” OR "emotional support" OR "emotional needs" OR "family support" OR “family	

		involvement” OR “family engagement” OR “family needs” OR “social needs” OR (MH "Interpersonal Relations") OR “interpersonal” OR (MH "Activities of Daily Living") OR “daily living needs” OR (MH "Bereavement") OR (MH "Grief") OR (MH "Personal Loss")	
#3	“Outcome of interest and individuals affected by testicular cancer”	1 AND 2 Limiters – English language and Peer Reviewed	172

Database: MEDLINE			
Date of Search: Date of Search: 17/11/2021			
Symbols used in this document:			
MH = Main Heading or “MeSH term”			
“ ” finds a phrase			
Asterisk (*) = truncates stem of a word			
Search #	**Concept/Explanation**	**Search Terms/Strategy**	**# of Results**
#1	“Population” – individuals affected by testicular cancer	“testicular cancer*" OR “testicular neoplasm*” OR (MH "Testicular Neoplasms")	27,282
#2	“Outcomes of interest”	"unmet supportive care needs" OR "patient needs" OR "care needs" OR "family needs" OR "caregiver needs" OR "supportive care" OR "supportive care needs" OR "heath system" OR "health information" OR "patient-clinician communication" OR "cognitive needs" OR (MH "Patient Care Team") OR (MH "Patient Comfort") OR "patient care needs" OR "multidisciplinary care team" OR (MH "Patient Care Planning") OR (MH "Patient Care Team") OR (MH "Patient Care Bundles") OR (MH "Patient Care") OR (MH "Patient-Centered Care") OR "person centered care" OR "family centered care" OR (MH "Progressive Patient Care") OR "continuity of patient care and oncology and palliative and primary care" OR (MH "Continuity	3,918,418

		of Patient Care") OR (MH "Respite Care") OR (MH "Social Support") OR "social networks" OR "social relationships" OR "support" OR (MH "Financial Support") OR (MH "Nutritional Support") OR (MH "Decision Support Techniques") OR (MH "Subacute Care") OR (MH "Ambulatory Care") OR (MH "Outpatients") OR (MH "Primary Health Care") OR "acute care" OR (MH "Inpatients") OR "hospital care" OR (MH "Health Planning Support") OR "behavioural symptoms" OR (MH "Symptom Assessment") OR "symptom management" OR "urinary symptoms" OR (MH "Signs and Symptoms") OR "Signs and Symptoms" OR (MH "Signs and Symptoms, Digestive") OR "Symptom Distress" OR "symptoms" OR (MH "Sexual Dysfunction, Physiological") OR (MH "Sexual Dysfunctions, Psychological") OR (MH "Sexual Health") OR "Sexual Dysfunction" OR (MH "Information Literacy") OR "information literacy" OR "information needs" OR (MH "Needs Assessment") OR (MH "Spiritual Therapies") OR (MH "Spirituality") OR (MH "Religion") OR "faith" OR "belief system" OR "spiritual needs" OR (MH "Hospice and Palliative Care Nursing") OR (MH "Palliative Care") OR (MH "Pain") OR (MH "Pain Measurement") OR (MH "Pain Management") OR "Human Needs" OR "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 (MH "Bereavement") OR (MH "Grief") OR "loss"	
#3	“Outcome of interest and individuals affected by testicular cancer”	1 AND 2 Limiters – English language and Peer Reviewed	2,061

Table 8. Quantitative 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**
Alacacioglu et al., 2014.	TCSs' physical functioning was lower than healthy controls.	There was not any statistically significant difference between the TCSs and healthy men, and the depression and anxiety rates of TCSs were lower than the control group.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	TCS had higher sexual dissatisfaction scores compared to healthy controls. There was a reduction in sexual functioning of the TCSs from 50 to 30 %. The effects of depression were associated with satisfaction, avoidance, touch, and erectile dysfunction.	Not reported.	Not reported.	Not reported.
Amidi et al., 2015a.	Not reported.	TCS had higher levels of stress than healthy controls ($p<0.001$).	Overall cognitive performance in TCS (M= -0.42, SD = -0.6) was lower than healthy controls (M= -0.01, SD = 0.6), (t(79) = -2.9, p= 0.004). Cognitive impairment was present in 58% of testicular cancer survivors and 24% of healthy controls (χ2 (1) = 8.9, p= 0.004). Impact of events scale – revised negatively associated with overall cognitive function (p = 0.04) Cortisol levels were associated with worse outcomes in 3/6 neuropsychological outcomes. C-reactive protein was associated with verbal fluency test outcomes (p = 0.05).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Amidi et al., 2015b.	Not reported.	Mean perceived stress (PSS) (SD): 14.6 (6.6) [4 – 39}. Mean depressive symptoms (BDI-II) (SD) [range] – 6.4 (7.0) [0 - 39}.	62.5% of TCS were cognitively impaired (N=45/72). CI was observed in multiple outcomes related to verbal learning and memory (29 to 33 % of participants), visual	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.

			learning and memory (14–28 %), processing speed (8–24 %), executive functioning (17 %), and attention and working memory (4–15 %). No association was found between treatment modality (surgery ± chemotherapy) and CI.								
Batehup et al., 2021. Mean number of unmet needs at T0 (SD) -2.01 (3.12) Mean number of unmet needs at T2 (SD) - 1.76 (3.88)	Not reported.	‘Help to cope with my concerns that my cancer will recur’ - 22% (N=9)/14.6% (N=6). ‘Help to reduce stress in my life” – 15%(N=6)/12.5%(N=5). ‘To help move on with my life” – 7.3%(N=3)/ 10%(N=4). ‘For others to acknowledge the impact of cancer on my life’ – 5.1%(N=2)/5.1% (N=2). ‘Emotional support for me’ – 9.8%(N=4)/9.8%(N=4). ‘Help to make decisions in uncertain times’ – 14.6%(N=6)/ 7.5% (N=3). ‘Help to make my life count’ – 4.9%(N=2)/7.5%(N=3). ‘Help to deal with beliefs that nothing bad will happen again’ – 12.2%(N=5)/ 5%(N=2). ‘Help to deal with other people’s expectations of me as a survivor’ – 15% (N=6)/ 5%(N=2).	Not reported.	‘To feel I can manage my health together with my health team’ – 10%(N=4)/2.4%(N=1).	‘My doctors to talk to each other to coordinate my care’ – (10%(N=4)/9.8% (N=4). ‘The very best medical care’ – 5.1%(N=2)/7.5%(N=3). ‘My complaints regarding my care to be properly addresses’ – 7.3%(N=3)/4.9% (N=2). ‘Understandable information’ – 2.5% (N=1)/4.9% (N=2). ‘Local health services available when I require them’ – 5% (N=2)/ 2.5% (N=1). ‘Up to date information’ 2.5% (N=1)/2.4% (N=1). ‘Information for family/others’ – 0% (N=0)/ 2.4% (N=1).	None	Not reported.	‘Help with problems with my sex life’ – (10% (N=4)/(10.3% N=4). ‘Help to adjust to change to the way I feel about my body’ – 7.5%(N=3)/ 7.5% (N=3).	Not reported.	‘Help to know how to support my partner/family’ – 7.3%(N=3)/ 7.3%(N=3).	Unmet supportive care needs at T0/T2: ‘To talk to other testicular survivors like me’ – 7.5%(N=3)/ 10% (N=4). ‘Help to know how to deal with the impact of cancer on my relationships’ – 7.3% (N=3)/7.3%(N=3). ‘Help to handle the topic of cancer in social/work situations’ – 4.9%(N=2)/2.5% (N=1). ‘Help to make new relationships’ – 2.4% (N=1)/2.5% (N=1).
Bender et al., 2012 62.5% of participants had one or more unmet needs Younger age, seminoma and treatment with chemotherapy,	Reports patients needing help with hair loss. Number unspecified.	‘reduce stress’ – 27% (N=53). ‘deal with my own of other’ expectations of me as a cancer survivor’ – 25.8% (N=51). ‘manage my concerns about the cancer coming back’ – 25.3% (N=50).	Not reported.	Not reported.	‘community support services’ –20.8% (N=41). ‘access complementary or alternative therapy services’ – 21.6% (N=43). Help with decision to get a prothesis. Numbers not provided. Information for their family to know what to expect post after	Not reported.	Not reported.	‘adjust to the changed I feel about my body’ – 27.6% (N=55).	‘Find out about financial support of governmental benefits to which I am entitled’ – 28.1% (N=56).	Not reported.	‘handle the topic of cancer in social and/or work situations’ – 20.7% (N=41). ‘talk to others who have experienced cancer’ – 20.4% (N=41).

radiotherapy, retroperitoneal lymph node dissection are associated with more overall needs (and met needs) Unemployed patients were more likely to have unmet needs when compared to employed patients		'adjust to the changes in quality of life as a result of cancer' – 19% (N=38). 'help to move on with my life' – 19% (N=38)			treatment. Numbers not provided.						
Brand et al., 2015.	Concern about having one testicle – 10% (N=2). Concern over physical appearance – 10% (N=2).	Not reported.	Not reported.	Not reported.	Information on sexual issues was provided to 78% (N=15) of TCS at diagnosis. Information had a 78% satisfaction rate. Information on sexual issues was wanted by 58% (N=11) of participants at diagnosis and 40% (N=8) post diagnosis.	Not reported.	Not reported.	Concern about sex life – 25% (N=5). Concerns about finding a partner – 10% (N=2). Concerns about fertility – 30% (N=6). Concern about testosterone level – 25% (N=5).	Not reported.	Concerns about the ability to have children (30%, N=6)	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**
Bumbasirevic et al., 2013.	18% (N=36) TCS had abnormally high levels of fatigue.	Emotional vitality was rated lowest in the EORTC and QLQ-30 (Mean =77.89). Mild depression present in 10% (N=22) and moderate depression was present in 2% (N=4) of TCS. Age is a risk factor for developing depression (OR03.2, 95 % CI 1.3–8.1, p00.012). Depression is associated with fatigue (r=0.589, p=.001).	Not reported.	None reported.	Not reported.	Not reported.	Not reported.	27.3% (N=55) of TCS reported worse sexual function compared to before treatment. Self-reported impaired erectile function present in 20.8% (N=42) of TCS Self-reported impaired ejaculation present in 25.7% (N=52) of TCS. Loss of sexual desire reported by 17.3% (N=35) of TCS. Ejaculatory dysfunction is associated with poor scores in bodily pain, general health, role-	Not reported.	Not reported.	Not reported.

								physical, physical functioning, composite scores and total scores in the Short Form 36.			
Darabos and Hoyt., 2017.	Not reported.	Clinical depression – 12.9% (N=22). Anxiety disorder – 9.9% (N=17). Future worry (b = -0.16, p < 0.05) and perceived stress (b = -0.36, p < 0.001) in testicular cancer survivors is linked to poor physical wellbeing [F(8,159) = 16.27, R2 = 0.44]. Physical wellbeing was associated with mental health history (anxiety (r = -0.30, p < 0.001), depression (r = -0.28, p < 0.001)	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
De Padova et al., 2011.	23% (N=10) of patients/caregivers reported 'quite a lot/a lot' of fatigue. 25% (N=11) of patients/caregivers reported 'a lot/quite a lot' of infertility.	35% (N=15) of patients/caregivers reported psychological distress was 'quite a lot/ a lot' relevant. 42% (N=18) of patients/caregivers reported fear of recurrence was 'high/very high' in TCS.	Not reported.	5% (N=2) of patients/caregivers reported experiencing 'a lot' of difficulties in relationships with their healthcare providers.	90% of patients/caregivers reported websites about cancer and survivorship were 'important/fundamental'.	Not reported.	Not reported.	14% (N=6) of 'patients/caregivers reported none/a little problems in sexual life'.	19% (N=8) of patients/caregivers reported 'quite a lot/a lot' of difficulties in work and/or study.	9% (N=4) of patients/carers reported experiencing 'quite a lot/ a lot' of problems in family relationships. 12% (N=5) of patients/carers reported experiencing strain in their relationship with their partner.	14% (N=6) of patients/caregiver reported TCS social relationships were made 'quite/very difficult' by TC.
Dimitropoulos et al., 2015.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	PC-RPLND patients experienced decreased satisfaction from intercourse post-surgery (4.57 ± 0.80 vs 1.94 ± 0.67 (p=0.000)). PC-RPLND patients experienced decreased sexual intercourse enjoyment post-surgery (4.57 ± 0.80 vs 2.06 ± 0.63 (p=0.000)). PC-RPLND patients experienced decreased frequency of ejaculation post-	Not reported.	Not reported.	Not reported.

								surgery (4.96 ± 0.20 vs 1.21 ± 0.81 (p=0.000)). PC-RPLND patients experienced decreased frequency of orgasm post-surgery (4.56 ± 0.19 vs 4.60 ± 0.69 (p=0.019)). PC-RPLND patients experienced decreased satisfaction with overall sexual life post-surgery (4.34 ± 0.96 vs 1.69 ± 0.61 (p=0.000)). PC-RPLND patients experienced decreased satisfaction with overall sexual relationship post-surgery (4.74 ± 0.44 vs 1.88 ± 0.77 (p=0.000)). 100% of PC-RPLND patients experienced total loss of antegrade ejaculation.			

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**
Kerns et al., 2020.	TCS who received cisplatin experienced: Obesity – 69.1% (N=1254). Peripheral sensory neuropathy – 55.3% (N=1004). Patient -reported renal disease – 2.4% (N=44). eGFR-defined renal disease – 50.1% (N=489). Tinnitus – 39% (N=708). Patient-reported hearing loss – 37.9% (N=688). Raynaud phenomenon – 32.5% (N=590). Autonomic neuropathy – 26.6% (N=483). Hypertension – 8.5% (N=154).	TCS who received cisplatin experienced: Anxiety and/or depression – 5% (N=91).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	TCS who received cisplatin experienced: Erectile dysfunction – 26.9% (N=489).	Testicular cancer survivors were more likely to be unemployed when compared to population norms Pain was more common in people on disability leave than those who were working full time	Not reported.	Not reported.

	Pain – 24.2% (N=440). Hypercholesterolemia – 6.8% (N=123). Hypertriglyceridemia – 0.4% (N=8). Thromboembolic event – 6.8% (N=124). Peripheral artery disease – 4% (N=72). Diabetes – 3% (N=54). Thyroid disease – 2.6% (N=47). Coronary artery disease – 2.5% (N=45). Transient ischaemic attack – 0.6% (N=10). Stroke – 0.5% (N=9). Hypogonadism – 8.5% (N=154).										
Nord et al., 2015.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	TCS take more sick leave than population comparators. Year after diagnosis - 64% (compared to 12%). Risk of work loss persists to the third year of follow up Patients who did not have more than 4 treatments did not experience work loss after 1 year.	Not reported.	Not reported.
O’Carrigan et al., 2014.	33% of TCS had hypogonadism.	Anxiety subscale Normal – 81% (N=44) Mild – 13% (N=7) Moderate – 6% (N=3) Severe – 0% (N=0) Depression subscale Normal – 94% (51) Mild – 6% (N=3) Moderate – 0% (N=0) Severe – 0% (N=0)	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Oechsle et al., 2016.	Symptom frequency/rated distress: Lack of energy (49%/21%), tiredness/drowsiness	Symptom frequency/rated distress: Don’t look like self (4%/1%), irritability (47%), feeling worried	Symptom frequency/rated distress: Difficulty concentrating (32%/8%)	Not reported.	Not reported.	Not reported.	Not reported.	Reduced sexual interest (22%)	Not reported.	Not reported.	Not reported.

	(42%/9%),pain (29%/8%),hair loss (13%/2%), sleep disturbances (36%/10%), itching (17%/4%), cough (17%/3%), sweats (29%/9%), shortness of breath (15%/3%), dizziness (15%/2%), skin changes (10%/3%), mucositis (9%/1%), numbness and tingling (29%/9%), feeling bloated (9%/3%), food taste (6%/3%). Problems with urination (6%/2%). Constipation (5%/1%). Diarrhea (11%/2%). Average number of physical symptoms – 4.5 (SD = 4.4; range, 1–28). Unemployed patients (when compared to employed patients) (r = 0.28, p < 0.001), lower socioeconomic status (r = −0.20, p = 0.02) patients and older patients s (r = 0.19, p = 0.01) were more likely to experience more physical symptoms	(42%), sadness (27%), Nervousness (24%) Average number of psychological symptoms - 1.4 (SD = 1.4)									
Pallotti et al., 2019.	Hypogonadism was present in 4.1% of TCS and none of the controls.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Pre chemotherapy (post orchiectomy) - Erectile dysfunction present in 91/241 (37.8%) of TCS and 22/223 (9.9%) of controls. Post chemotherapy erectile dysfunction returned to levels similar to the control group. TCS experienced consistently worse sexual desire, intercourse satisfaction and general	Not reported.	Not reported.	Not reported.

								satisfaction than controls.			
Püse et al., 2012.	Some testicular cancer survivors experience chronic pain. Numbers not provided. Percentages not reported. Chronic pain effects sexual functioning.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	TCS experienced: Reduced sexual desire - 34.5%. Reduced sexual activity – 41.6%. Erectile dysfunction – 31.5%. Inability to maintain erection during intercourse – 24.4%. Ejaculatory disorders – 84.9%. Reduced orgasm intensity - 32.4%. Reduced sexual satisfaction – 95.4%. .	Not reported.	Not reported.	Not reported
Shen et al., 2016.	Not reported.	16.7% of TCS felt discouraged about their health problems 'a good bit of the time' or more frequently. N=values not provided. Health distress scores were higher in TCS with education above secondary level (P = 0.031). 23.5% of TCS felt fearful about their future health ' a good bit of the time' or more frequently. N=values not provided. 23.5% of TCS worry about their health 'a good bit of the time' or more frequently. N=values not provided. 29.4% of TCS are frustrated by their health problems 'a good bit of the time' or more frequently. N=values not provided. 68.7% (N=57/83) of TCS were satisfied with the emotional support from their providers of care.	Not reported.	76% (N=57/75) of TCS felt their providers understood their expectations, beliefs and preferences. 74.1% (N=63/85) of TCS felt "known" by their care providers 91.9% (N=79/86) of TCS had confidence in the providers involved in their care. 80.8% N=59/73) of TCS felt prepared for discharge.	Young TCS (<40 years; P ¼ 0.013) and those who were not married or de facto (P < 0.045) have lower survivorship knowledge than those who are older and are married or de facto . TCS younger than 40 years were less likely to report being given education, self-management tools and patient resources (P = 0.05) and had lower Information Transfer and Management of Follow-up care scores (P = 0.05). 43.3% of TCS know about supports available to them. N=values not provided. 58.8% of TCS know how to 'manage their health risks'. N=values not provided. 58.9% of TCS 'know the chances or their cancer coming back' and the 'likelihood of them getting another type of	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.

					cancer’. N=values not provided. 64.5% of TCS ‘know the health risks and long-term effects’ of their cancer treatments. N=values not provided. 74.1% of TCS know ‘what screening tests’ they need to undergo. N=values not provided. 76.6% of TCS ‘know the stage’ of their cancer. N=values not provided. 85.3% of TCS know what treatments they have undergone. N=values not provided. 87.8% of TCS’ know what doctor’ they need to see and the frequency they need to see them. N=values not provided. 90.8% (N=79/87) of people were ‘provided clear information’ on their diagnosis 87.5% (N=77/88) were ‘provided clear information’ on prognosis 61.8% (N=47/76) were ‘told about nonurgent symptoms that may occur and how to cope with them’ 71.2% (N=52/73) were given information on ‘symptoms that require urgent medical attention and who to contact if they occur’ 79.6% (N=39/49) were ‘given complete information; on their medications						

					94.1% (N=80/85) were 'given information on follow up appointments' 81.1% (N=60/74) were 'informed of ongoing treatment that may be necessary after discharged and whether they would have ongoing contact with providers of my care' 76.8% (N=63/82) had 'a well developed and realistic follow up care plan prepared and explained' to them. 29.3% (N=22/75) were 'informed of self-management tools and education materials' that could help them 39.2% (N=31/79) were 'informed of patient resources/supports that may be available.' 31.8% (N=21/66) report their 'informal caregivers were given information on resources/supports'						
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**
Skaali et al., 2011a.	Not reported.	Not reported.	N=42/122 TCP had a cognitive decline of more than >10% from baseline. Associated with increased hearing loss/tinnitus (p=0.03). Not related to any other variables.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Skaali et al., 2011b.	Neurotoxic symptoms (SCIN): Peripheral neuropathy, baseline/follow-up: 4% (N=5)/15% (N=18) Raynaud-like symptoms, baseline/follow-up: 9% (N=11)/25%(N=31) Tinnitus or hearing	Not reported.	Testicular cancer treatment resulted in a neuropsychological decline in 34% (N=42) patients. This was not found to have statistically significant related to increase in self-reported cognitive problems	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.

	loss, baseline/follow-up: 9% (N=11)/25%(N=31)		(*P*=.82) 20% (N=25) of TCP had more self reported cognitive functions at follow up when compared to baseline. They were also more likely to have received chemotherapy (96% vs 69%), experience Raynaud-like symptoms (42% vs 16%), have a lower education level (68% vs 44%), a history of psychological problems (48% vs 19%), increased fatigue score (50% vs 22%). More TCPs who received a single (29%) or multiple chemotherapy sessions (25%) reported increased cognitive problems than TCPs who did not receive chemotherapy. Increased self-reported cognitive problems were positively associated with psychological distress								
Skaali et al., 2011c.	Not reported.	24% of newly diagnosed TCS had cancer related distress (95%CI 17%-31%).	Time used on Color-Word Interference Test (CW) 1 (used to measure psychomotor speed) and 3 (used to measure executive function) was associated with Impact of Events Scale (IES) scores (used to measure trauma) (adjusted p=0.04, adjusted p=0.03).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Smith et al., 2013. 66% of TCS reported one	Not reported.	TCS reported needing [Mean (CI) strength rating]:	Not reported.	TCS reported needing [Mean (CI) strength rating]:	TCS reported needing [Mean (CI) strength rating]:	Not reported.	Not reported.	TCS reported needing [Mean (CI) strength rating]:	TCS reported needing [Mean (CI) strength rating]:	Not reported.	TCS reported needing [Mean (CI) strength

or more unmet needs Mean number of unmet needs - 4.73 (SD = 7.0, Range = 0–34) Unmet needs per domain: Information– 0.32 (SD = 0.76), Relationships– 0.50 (SD = 0.90), and QoL–0.26 (SD = 0.61) Chronic illness (b = 0.189, p = 0.01, sr2 = 0.03) and young age (b = 0.188, p = 0.04, sr2 = 0.02) was associated with increases number of unmet needs (b = 0.189, p = 0.01, sr2 = 0.03) Radiotherapy was positively related to need strength (b = 0.161, p = 0.04, r2 = 0.03) Chemotherapy was negatively associated with need strength (b = 0.196, p = .01, r2 = .04).		‘help to reduce stress in my life’ – 30% (N=72/239) [1.89 (1.71,2.07)] ‘help to manage concerns about my cancer coming back’ – 22% (N=52/239) [1.79 (1.59,2.21)] ‘help to cope with others not acknowledging the impact that cancer has had on my life’ – 18% (N=42/240) [1.71 (1.45,197)] ‘help to deal with my own and/or others expectations of me as a “cancer survivor”’ – 17% (N=41/240) [1.63 (1.39,1.88)] ‘emotional support to be provided to me’ – 17% (40/240) [1.80 (1.55,2.05)] ‘help to make my life count’ – 13% (N=32/240) [2.03 (1.76,2.30)]		‘to know that all my doctors talk to each other to coordinate my care’ – 14% (N=33/238) ‘to feel like I am managing my health together with the medical team’ – 8% (N=19/238) [2.12 (1.76,2.48)]	‘the very best medical care’ – 7% (N=17/239) [2.47 (2.10,2.84)] ‘any complaints regarding my care to be properly addressed’ – 9% (N=21/238) [2.29 (1.96,2.61)} Mean number of unmet information needs information–0.32 (SD = 0.76) ‘local health care services that are available when I require them’ – 11% (N= 26/239) [2.08 (1.76,2.40)]			‘help to address problems with my/our sex life’ – 23% (N=56/240) [1.76 (1.56,1.97)] ‘help with having a family because of fertility problems’ – 11% (N=26/236) [2.35 (2.05,2.65)]	‘help to find out about financial support or government benefits to which I am entitled’- 22% (N=52/239) [1.98 (1.75,2.21)] ‘getting life and/or travel insurance because of my cancer’ – 20% (N=42/240) [2.08, (1.86,2.31)] ‘more accessible hospital parking’ – 17% (41/239) [2.05 (1.78,2.32)]		rating]: ‘help to talk to ithers who have experienced cancer’ – 17% (N=41/240) [1.68 (1.43,1.93)] Mean number of unmet supportive care needs related to relationships 0.50 (SD = 0.90),
Smith et al., 2016.	TCS have lower mean physical functioning than the age and gender adjusted Australian general population mean (52.82/53.32). TCS have lower mean physical role	TCS had higher mean levels of depression (48.64, SD=10.06) vs. 51.07, SD=12.78; t(243)=2.97, p=0.003) and anxiety (48.27, SD=10.19 vs. 50.73, SD=14.07; t(243)=2.73, p=0.007) than the age adjusted population.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	27% of TCS reported being “not at all” or “a little bit” interested in sex. (N=values not provided). 41% of TCS reported being “not at all” or “a little bit” sexually active	Not reported.	Not reported.	TCS have lower mean social functioning than the age and gender adjusted population (48.09/51.12).

	functioning than the age and gender adjusted general population (50.44/52.02). TCS have higher mean bodily pain than the age and gender adjusted general population (52.86/51.31). TCS have lower mean general health than the age and gender adjusted population (48.48/ 51.44). TCS have lower mean vitality than age and gender adjusted population (48.59/51.93). Low health related quality of life is positively rated to job problems (β=−0.38, p<0.001) 31% of TCS reported high levels (“very much” or “quite a bit”) of concern about their fertility. (N=values not provided).	TCS had lower mean emotional role functioning than age and gender adjusted populations (44.97/51.10). TCS had lower mean mental health than the age and gender adjusted populations (44.79/50.81). TCS had lower mean mental component summary scores than the age and gender adjusted populations (43.59/50.44). 30% of TCS report high levels (“very much” or :quite a bit”) of fear of recurrence. (N=values not provided). 29% of TCS reported high levels (“very much” or “quite a bit”) of uncertainty about the future. (N=values not provided). 26% of TCS reported high levels (“very much” or “quite a bit” of concern around the disruption testicular cancer had caused in their lives. (N=values not provided). 15% of TCS reported high levels (“very much: or “quite a bit”) of concern about their masculinity because of their diagnosis and treatment. (N=values not provided). Total support was negatively associated with stress (β= −0.25, p=0.001) and depression (β=−0.18, p=0.003)						27% of TCS reported being able to talk to their partner or the person closest to them about sex “a little bit” or “not at all”. (N=values not provided). 22% of TCS who received a prosthesis were “a little bit” or “not at all” satisfied with their outcome. (N=values not provided).			

		Helpless coping style as positively associated with depression (β=0.46, p<0.001), stress (β=0.23, p=0.007), and anxiety (β= 0.20, p=0.003). "Unmet needs uniquely explained 2 % of the variance in both depression (β=0.19, p=0.002) and anxiety (β= 0.20, p=0.003)". Low mental health quality of life was associated with reduced sexual activity (β=0.22, <0.001,.helpless/hopeless coping style a helpless/hopeless coping style (β=−0.31, p<0.001) and low social support (β=0.21, p=0.001)									
Soleimani et al., 2021.	Physical concerns of AYA and non-AYA patients were not different in a statistically significant way. Shared concerns included sleep 24.7% vs. 25.4%, p = 0.879), weight (17.2% vs. 13.1%, p = 0.320)" and concentration/memory (18.9 vs. 11.5%, p = 0.072).	35.2% (N=123) of TCS had self-reported symptoms of anxiety AYA had higher rates of self-reported anxiety symptoms (39.2% N=89) than non-adolescents and young adults (27.9% N=34) AYA reported more frustration/anger than non-adolescents and young adults (26% vs. 16.4%, p = 0.041)	Not reported.	Not reported.	37.9% of AYA and 36.1% non-AYA, p = 0.74) were concerned about their understanding of their illness and the treatments they had undergone.	The least concerning areas for both AYA and non-AYA were faith (11.2% vs. 0.7% p < 0.001) and the meaning of life (12.4% vs. 2.2% p = 0.002)	Not reported.	Not reported.	More AYA had concerns about work and/or school than non-AYA (38.3% vs. 18.9%, p < 0.001) More AYA had concerns about finances than non-AYA (34.9% vs. 18.9%, p = 0.002)	More AYA reported being worried about their family and friends than AYA (21% vs 19.7%) (p= value not reported)	Not reported.
Stouten-Kemperman et al., 2015.	White matter hyperintensities were higher in TCS treated with chemotherapy [χ^2 (2, N = 45) 5 5.29, P = 0.07]. Radial kurtosis was higher in TCS treated with chemotherapy (F_{143}= 4.36, p= 0.043).	TCS treated with chemotherapy had more body change concerns han those treated with surgery alone (p= 0.003).	TCS treated with chemotherapy had more self reported cognitive problems than those treated with surgery alone (35.7 vs. 4.3%, v2 (2, N = 51) = 7.34, P = 0.007)).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	14.8% (N= 4) of TCS treated with chemotherapy reported that workplaces changes were necessary to facilitate their return to work. Not statistically significant. 11% (N=3)of TCS treated with	Not reported.	Not reported.

									chemotherapy got a new job. Not statistically significant.		
Tasdemir et al., 2012.	Not reported.	TCS who had undergone chemotherapy had higher levels of anxiety than the general population (mean ± standard deviation) 45.0 ± 12.7 vs 10.1 ± 6.8 ($P < 0.05$). (N= values not reported).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	TCS who received chemotherapy were more likely to experience erectile dysfunction than healthy controls $P < 0.05$)	Not reported.	Not reported.	Not reported.
Vehling et al., **2021.** 33% of TCS report one or more negative changes [mean = 1.1 (SD = 2.5)]	Mean physical symptom count (SD) – 4.5 (4.3)	TCS reported negative life changes including: Negative life changes were reported by 33% of TCS. On average 1.1 changes was reported (SD = 2.5). <u>Depression (mean):</u> Low to mild – 92.1% (N=151). Moderate to high – 7.9% (N=13). <u>Anxiety (mean):</u> Low to mild -93.9% (N=154). Moderate to high – 6.1% (N=10).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Vehling et al., 2016.	49% of TCS report lack of energy. (N= value not reported). 42% of TCS report feeling drowsy. (N= value not reported). 36% of TCS report sleeping problems. (N= value not reported). Increased levels of physical symptoms were associated with increased anxiety and depression (anxiety: b=0.55, 95% CI=0.41 to 0.69, P≤0.001, depression: b=0.62, 95% CI=0.49 to 0.75, P≤0.001).	Moderate anxiety was present in 6% (N=10) of TCS. Moderate depression occurred in 8% (N=13) of TCS. Anxiety and depression were more likely to occur if a survivor had children [anxiety: b=0.43, 95% confidence interval (CI)=0.15 to 0.71, P=0.003, depression: b=0.37, 95% CI=0.11 to 0.62, P=0.006]. Younger age and diagnosis is associated with increased anxiety (b=−0.21, 95% CI=−0.37 to −0.06, P=0.01). Increased time since diagnosis was associated	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.

		with lower anxiety (b=−0.15, 95% CI=−0.29 to −0.01, P=0.04). Negative life changes are associated with anxiety (β = 0.23, 95% CI 0.11 to 0.36), and depression (β = 0.15, 95% CI −0.03 to 0.27)									
Wang and Hoyt, 2020.	Not reported.	Cancer related masculinity threat score in TCS (M = 2.43, SD = .64) Depression score in TCS (M = 12.99, SD = 12.08) Negative affect score in TCS (M = 1.80, SD = .74) Cancer related masculinity threat was associated with negative affect (r = .50, p < .001) and depression (r= .50, p < .001).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Wefel et al., 2014.	Not reported.	Not reported.	TCS who received chemotherapy experienced cognitive decline (on more than two tests) post treatment (low exposure – 17% vs high exposure – 29%). The surveillance group had no decline. Not statistically significant when compared to surveillance group (p=0.280, p= 0.08). Overall decline (on more than two tests) from post treatment to 12 month follow up occurred in 52% of TCS who had low exposure to chemotherapy and 67% of TCS who had high exposure to chemotherapy. Statistically significant when compared to surveillance group (p=0.006, p=0.001)	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.

			Young age was associated with cognitive decline.								
Wefel et al., 2011.	Not reported.	10% (N=7/69) of TCP had depression and 7% (N=5/69) TCPs had anxiety.	46% (n=32/69, p=0.0001) were considered cognitively impaired.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.
Wortel et al., 2015.	48% of TCSs reported concerns about fertility. 23% had concerns that were moderate – severe. More common in young patients (Spearman's r=-0.555, p=<0.001).	51% of TCS reported minor changes in body image post orchiectomy. An additional 10% reported moderate – severe changes. No correlation with age (p=.233). Not present in prothesis patients. 19% of TCS reported concerns about undressing around other men after orchiectomy. More common in young patients (Spearman's r=-0.194, p=0.014). Not present in prothesis patients.	Not reported.	Not reported.	44% of TCS had not received information on prosthesis.	Not reported.	Not reported.	When compared with baseline surveys, 6 months surveys indicate reduced erectile rigidity in TCS (p=0.016, 33% vs 25%). Body image changes were correlated with lower sexual functioning (erectile rigidity p=0.032, sexual pleasure p=0.021, sexual interest p=0.043, erectile function p=0.002) 23% of TCS had a reduction of sexual pleasure, sexual interest and activity six months post radiotherapy (p= 0.01). 45% of TCS reported negative effects on sex life. N=14 had moderate tp severe effects. Poor body image was had adverse effects on sex life (Spearman's r=0.267, p=0.003). Erectile rigidity, sexual interest, sexual satisfaction, erectile dysfunction, sexual pleasure and sexual activity were associated with worse sexual life (p=<0.01). 13% of TCS reported experiencing sexual difficulties with their partner due to have one testicle. More common in young patients (Spearman's r=-0.225, p=0.004). Not present in prothesis patients.	Not reported.	Not reported.	Not reported.

Testicular cancer survivors (TCS), testicular cancer (TC); testicular cancer patients (TCP); adolescents and young people (AYA).

Table 9: Study Findings and Illustrations

Authors: Carpentier et al., 2011					
Findings	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
Adolescents and young adults are embarrassed by their symptoms of testicular cancer and delay seeking care as a result.	When I went to the emergency room, the check-in desk at the emergency room, there was two young girls working there. I’m only 25 years old and they kept asking me what the problem was and I kind of pointed down there… I was embarrassed to say that I have a big knot down there’ (Participant 19)” (page 741).		**Yes**		**1**
Masculinity prevented testicular cancer survivors from seeking immediate care	“‘I happened to just check one day and I was like ‘Oh!’ and a month later I went to the doctor it’s just the stubbornness of a guy, okay, it’s not a big deal’ (Participant 2) (page 741) “‘Most guys have that ego where, ah, it’s probably nothing. I had that same ego at the time, I’ve never had the flu or anything, so I’m like there’s no way I’m sick. Yeah, I’d definitely say it’s the masculinity that gets in the way’ (Participant 17).” (page 741)	**Yes**			**2**
Adolescents and young adults who had testicular cancer feel different from their peers as a result of their cancer.	“‘You consider life a little bit differently and your realities would be for a shorter time period instead of longer so, yeah, there are some changes, especially on my values’ (Participant 4)” (page 741). “‘I look at things differently than a lot of people though, so I’m kind of a little bit on the abnormal area, I suppose’ (Participant 1)” (page 741). “‘They know that I had cancer, but to them, if it didn’t kill you then you’re fine… they don’t know how I feel, they don’t know how I think, they don’t know what it feels like but they’ll tell you ‘well, you ought to do this or I would do this.’ They don’t know, they don’t have a clue’ (Participant 19).” (page 741)		**Yes**		**3**

	"'When I got married I guess because of being a cancer patient I felt like the marriage was, I took it a little more seriously than I might have before' (Participant 1)" (page 741) "'It was better for our relationship, it made us realize that we wanted to be together, and so settled me down from, got me more focused on maturing and growing up, stuff like that. So, if anything, it was better for our relationship.'" "'They said one of the things that can happen is infertility, and I thought with all the health problems that I had, I do not want to pass it onto somebody else, no, no, no, definitely not. My thought is if they ever wanted kids, I would probably adopt, as opposed to making my own… I guess it's just something I will deal with when the time comes' (Participant 13)." (page 741-742)				
Adolescents and young adults felt that being different made them "damaged goods".	"'Losing my hair was probably more devastating than losing my testicle I think. Because I went from liking my hair to having none in about three days. And that was a big adjustment. Even though a lot of guys you see on the street shave their head, and have short hair when it first happened midway through the chemotherapy… I hadn't shaved in three or four days or whatever, it was just falling off. That was probably as devastating as anything, for me. It was just like, 'wow' (Participant 1)" (page 742). "'Because the scar, especially from the radical lymph node dissection, is quite obvious. It's like, a twelve inch scar is hard to hide. That's probably the biggest problem. Is that even if I did not want to tell anyone, there's no point in lying' (Participant 9)		**Yes**		**4**

	‘It just feels kind of like you’re incomplete. Just as a person you feel like you’re missing something you’re supposed to have. I guess it’s just the fact that it doesn’t have any real effect but there’s still something missing. So it’s just that weird dichotomy’ (Participant 9)” (page 742). “‘It’s just the part about being a man and the man having that ability to, and also losing part of that is like losing a part of yourself’ (Participant 2) (page 742) ‘There was a time in the first intimate moments and you’ve had your testicle removed, you’re a little unsure of yourself’ (Participant 1)” (page 741). “‘It’s something I’ve always had so losing any kind of body part, organ or anything just, you know you’ve only got one left. So, if it gets compromised and it has to be taken out at least I guess it’s not a lung or’ (Participant 6)” (page 741).				
Adolescents and young adults find disclosing their history of cancer challenging	“‘I do have a few hang-ups about it, just saying that I have cancer to new people. Pretty much towards potential romantic partners. Because in class I don’t have a problem if we’re discussing something like that, it doesn’t really bother me. But, of course, usually in class I don’t specify what type just because in my mind it takes it to a much more intimate conversation than if it was skin cancer’ (Participant 9)” (page 742). “‘I always wonder if it’s a first thing or, I don’t know. I guess it kind of depends on who the person is at this point, because I don’t really since I haven’t told anyone yet, I don’t really have any baseline to say, ‘well that was a really bad idea to say on the first date.’ Or, ‘wow, they got really mad because I didn’t tell them until two months into the relationship’(Participant 9)” (page 742).	**Yes**			**5**

	“‘I kind of don’t want to drag anybody into all of this stuff right now. It’s a lot of stuff to swallow, going through all of it. I guess my point of view is that I always just thought who would want to get involved right now?’ (Participant 5)” (page 742) “‘I had friends joking with me and stuff about it. It was all in good fun I guess but yeah sometimes it bothered me. I’m thinking, I’m fine now. You really can’t tell it’s not there’ (Participant 6).” (page 742)				

Authors: Martin et. al., 2013					
Findings	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
Patients need information needs regarding their health and healthcare are not adequately met.	““In that workshop . . . I found out more than I have done in the last probably six years of going through this.”” (Page E19) ““No one ever told me about self-examination.”” (page E19) ““My doctors have said, you know, live healthy and that but, you know, that workshop went a bit more into how to live healthy.”” (page E20) ““I just wish I had it when I first started going through it and I never did.”” (page E21)		**Yes**		**1**
An educational workshop met social needs of the testicular cancer survivors	““raises the whole agenda of how do you help patients to feel . . . that other people have been or are in the same situation.”” (page E20)		**Yes**		**2**

	““useful parts were actually having the opportunity to listen to other people, and it’s good to get the group talking about it.”” (page E20) ““To see how the others responded to it highlighted for me just how important it was . . . because some of them had had quite traumatic experiences and, therefore, to be able to verbalize it and find there are others who could empathize with that, and also to be give some direction to say, “Look, you can begin to manage that.” I thought it was good.”” (page E20) ““to be aware particularly of those that were on the same workshop whose conditions had been dramatically worse than mine and how they’ve, you know, responded to that actually put it back into perspective again.”” (page E20) ““it’s probably the one time where we will open up. . . . So the opportunity to discuss things is what’s needed.” The group was relaxed, which was important because “we can have a laugh and talk about it, it just made it more of a social event as well.”” (page E20)				

Authors: Matheson et. al., 2016					
Findings	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
Testicular cancer survivors expressed that it would have been beneficial or was beneficial to speak to someone.	“(‘that would have been nice to have had a mentor’ P18, T2, 44 years, single, Surgery + C + R)” (page 200)		**Yes**		**1**

	"'you can't bottle it all up' P23, T1, 30 years, in a relationship" (page 199) "'I just think it just helped just reassure me, like I wasn't a nutter, or some weirdo, and you're not the only person, you won't ever be the only person who's gone through it' (P20, T1, 22 yrs, Single, Surgery+C)" (page 199)				
Some testicular cancer survivors required more information around which members of the healthcare team to contact when they required help	"You just want someone to go, if you've got a problem go to your GP, or if not you phone this person, any questions phone this person, that would be the only thing, [health professionals'] just kind of go 'well you're fine you're fine' (P10, T1, 41 yrs, Married, Surgery)" (page 200)	**Yes**			**2**
Some testicular cancer survivors report struggling with mental health when returning to work	"'some days you feel absolutely fine and silly little things remind you that you actually had cancer…. for a while I felt low and yeah I admit to my wife I'd thought at some stages I was maybe suffering from depression….I felt not lonely, sort of very pressurised and was very snappy, and then all of a sudden out the blue you have a good week, two weeks and things are fine, but things easily build, got on top of me very quickly, so I'd come back down again, no I never went to the doctors or anything, from time to time I still do get these times, but I'm assume that's life of living with cancer, and a young family and pressures of life' (P1, T2, 36 yrs, Married, Surgery+R*)" (page 201)		**Yes**		**3**
When testicular cancer survivors experienced changes to their physical body due to their treatment, it affected their body image	"('you kind of lose a little bit of your identity' P2, T2, 24 years, single, Surgery + C*)" (page 201)		**Yes**		**4**
Some testicular cancer survivors struggled with their sense of identity	"'I don't at times feel good about myself, and then that worries me that I'm perhaps not as good as I should be for my wife and my child and everything else, and it does bother me.. but there doesn't seem	**Yes**			**5**

	to be an avenue you can go, to sort it’ (P10, T2, 41 yrs, Married, Surgery)” (page 201)				
Some testicular cancer patients expressed sadness	“(‘I wouldn’t say I’m back to total normal, no, not quite, I still don’t feel right’ P10, T2, 41 years, married, Surgery)” (page 202)		**Yes**		**6**
Some testicular cancer patients expressed that they felt their health was vulnerable	“(‘wait for the next thing to give up’ P10, T2, 41 years, married, Surgery)” (page 202)		**Yes**		**7**
Some testicular cancer patients felt resentment as a result of infertility brought on by treatment	“‘Just the resentment, you can’t be as you were… that one’s a bit more of a difficult one to get over, lots of our friends are obviously having babies…which is something that we feel that we’re more than prepared to do… so I know that I’ll never be able to look back on the cancer and think oh well that was a bit tough but I’m so glad it happened, there’s always going be a bit of hatred, bit of resentment there’ (P14, T2, 31 yrs, Married, Surgey+C*)” (page 202)	**Yes**			**8**

Authors: Saab et al., 2016					
Findings	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
Testicular cancer survivors did not want to disclose their diagnosis.	““My sister doesn’t know that I got sick with cancer...she still doesn’t know. I took chemotherapy and lost my hair...I didn’t want anyone to see me and go tell my sister.”” (page 206) ““My biggest worry was that I don’t want my parents to know about the subject...I told them that I have to undergo a surgery because I have a kidney stone...I took chemotherapy and told them that I am losing my hair while showering....”” (page 206) ““I didn’t want to tell anyone...especially here in our village, if they knew that I was sick, the news would spread in the whole village. Thank God, nobody knows.”” (page 206)	**Yes**			**1**

Testicular cancer and it’s treatments resulted in significant changes to the survivors lifestyle and outlook on life.	““After chemo, there was a time I used to play football but then I felt that my knees cannot hold me anymore so I stopped.”” (page 206) ““Up until now, from the time I do a CT scan...and the alpha feto [alpha-fetoprotein], I feel that I am in a different world.”” (page 206) ““The doctor told me to do them [follow-up tests] every six months, but I am doing them every three months for reassurance.”” (page 206) ““My life changed, it became healthy. I stopped smoking and stopped alcohol...I followed a totally different diet.”” (page 206) ““As long as I have a good health and as long as my outlook on life is right, I want to move forward and not take a step back...I forgot about the past...I have to evolve and grow; I can’t remain the same.”” (page 206)	**Yes**			
Testicular cancer and its treatments caused infertility and affected the survivors confidence.	““Chemotherapy took my fertility away...I can’t have kids anymore.”” (page 206) ““An infertile man... the way people perceive him makes him want to beat himself... I suffered...a man is about sex and kids to a certain extent.”” (page 206) ““If I want to propose to a girl and she would know that I have only one testicle, she might reject me.”” (page 206) ““My doctor told me to do a sperm count, I refused...the result would affect my psychological well-being....”” (page 206)	**Yes**			

Authors: Shen et al., 2016					
Findings	**Illustrations (Page number)**	**Evidence**			**Finding number**
		Unequivocal	**Credible**	**Unsupported**	
Testicular cancer survivors felt they were not prepared for what to expect after treatment	““I don’t know what to look for, I don’t know what to expect.” (page e16)	**Yes**			**1**

	““I don’t know what the symptoms would be if the cancer came back… I wasn't given any of that detail. I wasn't told how I should change my lifestyle, if I should change my lifestyle. They just said, keep on living the way you do.”” (page e16) ““Based on my personal experience, I don’t think we’re exactly prepared for after treatment, because it's kind of like, ‘whatever you have during treatment, that's the symptoms you're going to have after treatment. And we don't know how long it's going to take to come out-to go away, so deal with it until then.”” (page e16)				
Testicular cancer survivors had challenges in accessing reliable information and resources	““I saw a lot of things that really freaked me out on the internet that I probably shouldn't have looked at, and I wish that there was a specific guide or a specific like chapter that they refer me to... Don't start looking at all this other stuff… it spirals out of control. I was panicking…”” (page e16) ““There was no discussion that I remember that was any, you know, ‘if you're feeling like this, then come and talk to us,' or, you know, ‘there's counseling available,' or anything like that. I don't recall anything like that for the psychological side of any concerns, really.” “The attitude seemed to be, if something bothers you, tell us and we'll deal with it. We're not going to tell you in advance what any of those things might be.”” (page e16) “”There was no discussion that I remember that was any, you know, ‘if you're feeling like this, then come and talk to us,' or, you know, ‘there's counseling available,' or anything like that. I don't recall anything like that for the psychological side of any concerns, really.”” (page 16)	**Yes**			**2**

	““The onus always seemed to be on me to get in touch” “I think it would be great to have a document that contains all that information put together in a personalized way, just so the patient is aware of everything.”” (page e16) ““I think it would be great to have a document that contains all that information put together in a personalized way, just so the patient is aware of everything.”” (page 16)				
Testicular cancer survivors experienced emotional difficulties	““…the bounce back from this was something that I couldn't cope with emotionally because I've never really dealt with a lot of emotions…I'm a guy…you need to be strong and that's what I was taught and you just deal with it and suck it up…”” (page e16) ““By I think about three or four months [after going back to work] I just (clap!) I hit a wall and then all these emotional things came and I'm like whoa!” “I was fighting so long and then that died and then… a lot of emotional stuff came in.”” (page e16)	**Yes**			**3**
Testicular cancer survivors did not feel reassured by healthcare providers	““I felt sort of brushed aside. I had questions that weren't answered, like that were almost basically ignored.” “It's great to find out everything's all right, but I think you need a little bit more.”” (page e16)		**Yes**		**4**
Testicular cancer survivors wanted clearer communication about who to contact when they had concerns about their health	““So if I have a symptom that… you have a list of these possible symptoms… and I know to contact a particular person at the… hospital… who can tell me ‘you know what, you should go see your family doctor or, no, come see us.'”” (page e16)	**Yes**			**5**

Authors: Wibe et. al., 2012					
Findings	**Illustrations (Page number)**	**Evidence**			**Finding number**

		Unequivocal	Credible	Unsupported	
Patients had unmet information needs	““I was at a 4 weeks’ check-up with you last week. Took some blood tests then, which showed some values that were too high. I was originally supposed to come back to you after 6 weeks, but now I’ve got a new appointment already after 2 weeks. How should I interpret this—a bigger chance that there is something in my body? Many people say that these values on blood tests go up and down. So I am very unsure what to think. Can I say that I don’t have cancer any more now, until something more is discovered?” (message)” (page 3) ““... It (the information on the Internet) was a little contradictory ... [...] It said that there are two types (of testicular cancer): there is non-seminoma and there is another type. And one of them is bad and the other is not that bad. But as long as you don’t know what you have, it is really better not to read it, because ... I at least, became more worried. You start to think about the worst case, you know ...” (interview)” (page 4) ““It’s usually at the start of an illness that you have questions, and perhaps some extra need for support [...] ... Like after my first surgery at the local hospital and before I was admitted to the regional hospital—who could I talk to in the meantime?”” (page 5) ““... Yes, there was much that was still not clear, but on the other hand it would have been better to hear that “This is not clear yet, so you will have to wait until we have an answer to this and that before we can tell you”, rather than just: “We cannot answer you”. (interview)” (page 5)		**Yes**		**1**
Patients felt uncomfortable discussing sexual function	““Sexual questions for example, which might have come up during the doctors’ rounds ... This might be				

	easier to ask about in an e-mail to a person that you don’t know than when the doctor asks: “What about your ... (sexual function)?” Then you answer: “Oh, that’s OK” or “That’s normal” or whatever ... (interview)” (page 4)				
Patients had difficulty navigating the health system	““Hi, I’ve been trying to get in contact with Dr. X since I last was in the hospital, but nobody would put me through and nobody would leave a message—so now I am trying to get through here ...” (message)” (page 4) ““Hi. I got a letter yesterday about an X-ray examination on the 7th of March at 09.30. This is the same day that I have a consultation with the physician at 08.30. I figure that I will also go to the laboratory for a blood test that morning, before the consultation. I just want to make sure that the consultation will not conflict with the X-ray. If I have to wait for the consultation I risk arriving too late for the X-ray appointment”. (message)” (page 4)				