



OPEN ACCESS

# Supportive interventions for carers of men with prostate cancer: systematic review and narrative synthesis

Natalie Winter <sup>1</sup>, Hannah Jongbloed,<sup>1</sup> Anna Green,<sup>2</sup> Anna Ugalde,<sup>1</sup> Patricia M Livingston<sup>3</sup>

► Additional supplemental material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/spcare-2022-004034>).

<sup>1</sup>School of Nursing and Midwifery, Centre for Quality and Patient Safety Research in the Institute for Health Transformation, Deakin University, Burwood, Victoria, Australia

<sup>2</sup>Centre for Health Research, Faculty of Sciences, University of Southern Queensland, Springfield, Queensland, Australia

<sup>3</sup>Faculty of Health, Deakin University, Burwood, Victoria, Australia

## Correspondence to

Dr Natalie Winter, School of Nursing and Midwifery, Deakin University, Burwood, VIC 3125, Australia; [natalie.winter@deakin.edu.au](mailto:natalie.winter@deakin.edu.au)

Received 24 October 2022

Accepted 27 April 2023

Published Online First

1 June 2023



© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

**To cite:** Winter N, Jongbloed H, Green A, *et al.* *BMJ Supportive & Palliative Care* 2024;**14**:e173–e182.

## ABSTRACT

**Purpose** The objective of this study was to summarise the literature on current interventions available for carers of men with prostate cancer and analyse the outcomes of these interventions in supporting carers' needs.

**Methods** A systematic review was conducted, searching databases MEDLINE, PsycINFO, CINAHL, Scopus and Cochrane, using terms related to prostate cancer, carers and interventions. Randomised controlled trials and non-randomised controlled trials of interventions for informal carers with or without patients were included. Data were analysed using descriptive and frequency statistics; interventions and their impact on carers' outcomes were reported on narratively. The SwiM guidelines were applied to guide data synthesis.

**Results** Overall, 24 articles were included in the review. On average, participants were spouses (92%) and women (97%). Interventions largely were delivered face-to-face (42%) or used a combination of face to face and online modalities (38%). Two-thirds (63%) showed a significant improvement in carer's outcomes including psychological, sexual, physical and relationship/marital. The majority of studies (79%) tailored contents to carers' circumstances, most within a couples counselling format. Over one-third (42%) of studies focused on a range of supportive care needs, most commonly were psychological (58%), sexual (42%) and informational (25%).

**Conclusions** Interventions for carers of men with prostate cancer were largely face to face, patient-spouse focused and two-thirds had some measurable impact on carer's outcomes. Research continues to underserve other patient-carer roles, including non-spousal carers. Interventions delivered solely for carers are required to meet gaps in care, and determine the impact on carer outcomes. Further research and more targeted interventions are needed.

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Interventions for carers looking after someone with cancer have variable impacts on carers' outcomes.

## WHAT THIS STUDY ADDS

⇒ Most interventions include some level of tailoring to carers' supportive care needs; however, tailoring often occurs in dyad-based interventions such as couples counselling.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Findings inform the development of future interventions and current clinical practice where carers' supportive care needs to be addressed outside of the marital relationship.

## PROSPERO registration

number CRD42021249870

## BACKGROUND

In Australia, prostate cancer is the most common cancer type among men.<sup>1</sup> Despite being the second leading cause of cancer mortality among men, 5-year survivorship from prostate cancer is close to 100% for those diagnosed with stages' I–III.<sup>1</sup> With early diagnosis and improved treatment options, prostate cancer is now considered a chronic condition.<sup>2</sup>

Cancer is also considered a 'family disease', which has a significant impact on the daily lives and long-term health and well-being of close family members and friends.<sup>3</sup> Approximately, 70% of people undergoing cancer treatment have a family member who provides ongoing care at home,<sup>4</sup> these family members and other unpaid carers such as friends are

known as informal carers (hereafter, carers).<sup>5</sup> Understanding the role and influence of carers is a necessary component in developing resources to assist individuals providing care.<sup>6</sup>

Most carers will report experiencing at least one unmet need throughout and beyond the illness trajectory and carers often require assistance to address needs as they arise.<sup>7</sup> The type of support required by carers can vary across cancer stages and treatment types,<sup>8,9</sup> as different side effects are experienced within each treatment regime.<sup>10,11</sup> Carers can receive support in a myriad of ways, including informal social networks, formal support through government and hospital services, and through technology; linking with cancer organisations and online support groups.<sup>12,13</sup> There is a range of information, resources and support available to carers across different modalities including face to face and through technology, and in the community and outpatient setting; however, resources are commonly provided based on patients' needs.<sup>14</sup> Caregivers' knowledge of available support is dependent on their availability to attend outpatient appointments.<sup>14</sup> Carers can initiate seeking support; however, accessing information and support is a time-consuming task<sup>15</sup> and carers require adequate health literacy, knowledge and access, to properly navigate and understand health information.<sup>16</sup> In particular during crises, a lack of information and support can result in uncertainty and at times delays in seeking medical assistance.<sup>12</sup> Spouses and partners are family members who most commonly provide care to men with prostate cancer, and the patient–partner dyad can experience more specific unmet needs related to sexual function and marital relationships during and after treatment.<sup>17–19</sup> Early educational programmes can be used to promote couples' marital and sexual well-being prior to surgery.<sup>20</sup> Carers require additional support to confidently manage patients' side effects and symptoms<sup>21</sup> and assistance to maintain their own health and well-being.<sup>22</sup>

There is a pressing need to explore how interventions meet the supportive care needs experienced by carers. Within the wider cancer context, there is evidence that interventions are largely dyad based with intervention content focused on patient care.<sup>23</sup> Similarly, within the prostate cancer field, the best way to support carers looking after men with prostate cancer is still unclear; dyadic interventions have limited positive outcomes in female partners.<sup>24</sup> Technology-based interventions may play a role in improving carers' outcomes<sup>25</sup>; however, the full impact of these interventions requires further investigation. This review provides much needed information on how to support carers looking after men with prostate cancer.

### Aims

The aim of this review was to summarise the current literature on supportive care interventions for informal

carers of men living with prostate cancer and answer the following questions:

1. What supportive interventions have been evaluated to meet carers' needs?
2. What are the outcomes of these supportive care interventions?

### METHODS

This systematic review was registered on PROSPERO, registration number: CRD42021249870.

#### Search process

A systematic search was conducted in December 2020 and updated in January 2022 using the following databases: MEDLINE, PsycINFO, CINAHL, Embase, Scopus and Cochrane Database of Systematic reviews. References lists of articles included in the review were screened for additional articles meeting the inclusion criteria. Articles found through hand searching were included in the review. To gain a full understanding of the scope of research available, no date limits were applied. References were uploaded and organised in Covidence. Duplicates were removed and remaining resources were double screened by title, abstract (by NW, HJ and AU) and full text (by NW, HJ and AG; figure 1).

#### Search strategy

Search terms were developed by the whole research team and were reviewed by the research librarian. Search terms were developed for three main topics with subject heading applied to each database. An example of the strategy on the Medline database is outlined in table 1. Search terms for each topic were as follows:

1. Prostate cancer—prostate neoplasm\*, prostate, prostatic carcinoma\*, urologic carcinoma\*, urologic neoplasm\*, urologic cancer\*, prostate cancer\*.
2. Carers—carer\*, caregiver\*, spouse\*, famil\*, partner\*.
3. Supportive care interventions—program, intervention, counselling, therapy, community service\*, social network, cognitive behavioural therapy, CBT, support group, telephone, internet, web, smartphone application, mobile application, app, pilot, randomi?ed control trial, non-randomi?ed controlled trial.

#### Inclusion criteria

Criteria are presented according to the Population, Intervention, Control, Outcomes (PICO) framework.<sup>26</sup> Studies were included in this review if they met the following criteria:

- Population—interventions for partners and informal carers, identified as family members or non-family members who were providing care to men with prostate cancer.
- Intervention—interventions available to informal carers of men with prostate cancer including: face to face, online, telephone and studies using a combination of modalities to deliver intervention content.

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only

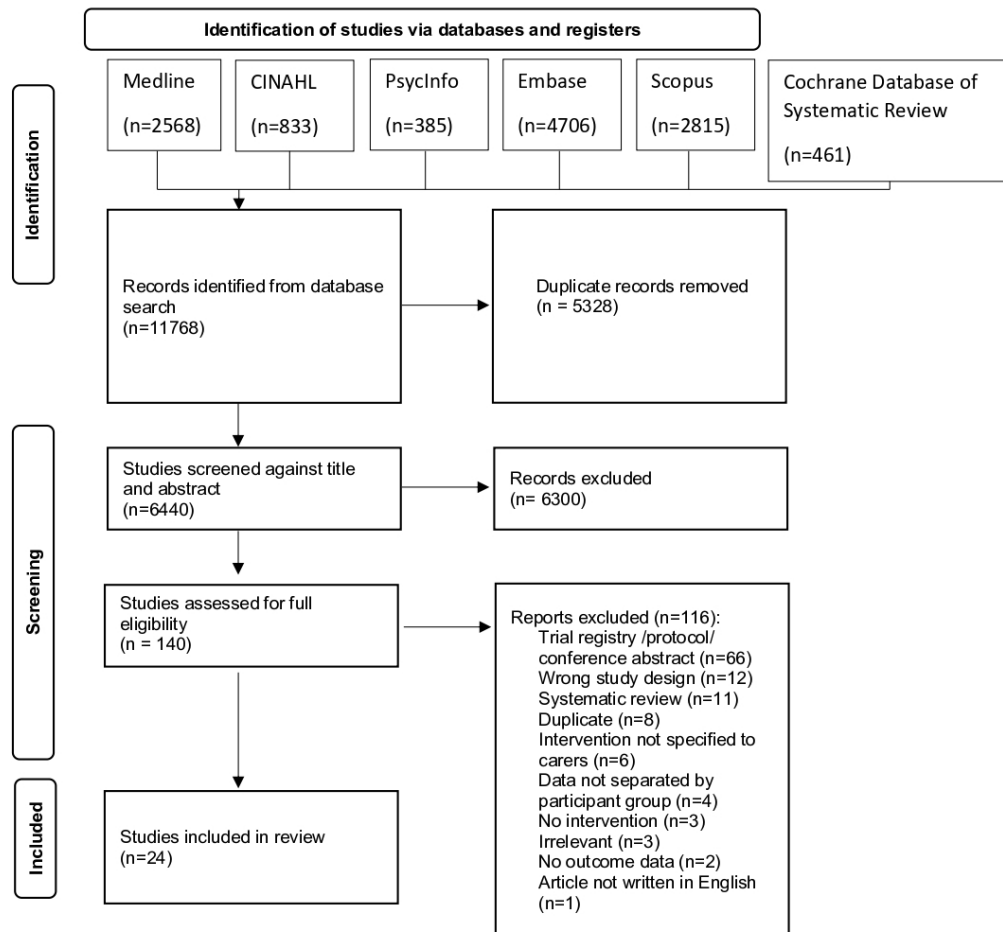


Figure 1. Prisma flowchart

Figure 1 Prisma flowchart.

**Table 1** Search strategy on Medline Complete database

Database (including platform for clarity of source, eg, Medline Complete (Via Ebsco)	Search strategy (Paste in the search strategy from the database, so others can replicate your search exactly.)
Medline Complete (Via Ebsco)	<p>S1 (MH "prostatic neoplasm*") OR (MH "urologic neoplasm*") OR (TI "prostate neoplasm*") OR (TI prostate) OR (TI "prostatic carcinoma*") OR (TI "urologic carcinoma*") OR (TI "urologic neoplasm*") OR (TI "urologic cancer*") OR (TI "prostate cancer*") OR (AB "prostate neoplasm*") OR (AB prostate) OR (AB "prostatic carcinoma*") OR (AB "urologic carcinoma*") OR (AB "urologic neoplasm*") OR (AB "urologic cancer*") OR (AB "prostate cancer*")</p> <p>S2 (MH Caregiver*) OR (MH spous*) OR (MH family) OR (TI Carer*) OR (TI caregiver*) OR (TI spous*) OR (TI famil*) OR (TI partner*) OR (AB Carer*) OR (AB caregiver*) OR (AB spous*) OR (AB famil*) OR (AB partner*)</p> <p>S3 (MH "self-help group*") OR (MH "cell phone") OR (MH "mobile application*") OR (MH "clinical trial") OR (MH "qualitative research") OR (MH pilot*) OR (MH "randomized controlled trial") OR (TI program) OR (TI intervention) OR (TI counseling) OR (TI therapy) OR (TI "community service*") OR (TI "social network") OR (TI "cognitive behavioural therapy") OR (TI CBT) OR (TI "support group") OR (TI telephone) OR (TI internet) OR (TI web) OR (TI "smartphone application") OR (TI "mobile application") OR (TI app) OR (TI pilot) OR (TI "randomi?ed control* trial") OR (TI "non-randomi?ed control* trial") OR (TI "clinical trial") OR (AB program) OR (AB intervention) OR (AB counseling) OR (AB therapy) OR (AB "community service*") OR (AB "social network") OR (AB "cognitive behavioural therapy") OR (AB CBT) OR (AB "support group") OR (AB telephone) OR (AB internet) OR (AB web) OR (AB "smartphone application") OR (AB "mobile application") OR (AB app) OR (AB pilot) OR (AB "randomi?ed control* trial") OR (AB "non-randomi?ed control* trial") OR (AB "clinical trial")</p> <p>S1 AND S2 AND S3            S1 AND S2 AND S3</p> <p>Limiters - Scholarly (Peer Reviewed) Journals            Narrow by Language: - english            Search modes - Boolean/Phrase</p>

- ▶ Comparators—all usual care and alternative intervention groups were included in the review.
- ▶ Outcomes—there were no restrictions on outcomes, studies could report on any supportive care outcomes including supportive care needs, psychosocial well-being and physical health.
- ▶ Studies included randomised controlled trials and pilot studies of interventions to address partner and carers needs.

Publications including carer/patient dyads were included if results relating to carers' support needs were reported separately.

#### Exclusion criteria

Studies were excluded in this review if they met the following criteria:

- ▶ Published in a language other than English.
- ▶ Focus on preventative screening of prostate cancer.
- ▶ Includes several types of cancer in their analysis where the specific needs of carers of men with prostate cancer cannot be distinguished.

#### Data extraction

For each included study, descriptive data were collected including: mean sample age, gender, ethnicity, race, recruitment and attrition rates, intervention modality, focus area of intervention and key findings. A data collection tool was created to collect data via Qualtrics and used a range of closed and open-ended questions. For example, close-ended questions included the target sample of the study (carers/dyads/other), study design (randomised controlled trial/pilot randomised controlled trial), intervention modality (face to face, online, telephone, hardcopy, other and types of unmet needs addressed in the intervention (information, support, marital etc)). Open-ended questions included age, sample size, recruitment rate, retention rate, description of the intervention and impact on outcomes. Data extraction was completed (NW, AG and HJ) with 20% cross-checked by NW. Ambiguities were discussed until a consensus was reached. Two studies reported on one set of data in a longitudinal approach<sup>27 28</sup>; we combined the findings of both studies during our analysis.

#### Data analysis

Data were analysed using descriptive and frequency statistics. Interventions and their impact on carers' needs were reported. A meta-analysis was not conducted due to the heterogeneity of the studies. The Synthesis Without Meta-analysis (SwiM) guidelines are recommended for use when a review is undertaken with no meta-analysis; we have applied these guidelines to our review.<sup>29</sup>

Studies were analysed in different groups, first by study design, where studies were grouped by randomised controlled trials, pilot studies and non-randomised clinical trials and were reported on in these groups. Second, studies were grouped by intervention

modality such as face to face, online or a combination of both modalities to describe differences in outcomes compared with intervention delivery.

#### Risk of bias

A risk-of-bias assessment was completed using the Cochrane risk-of-bias tool. Risk of bias was completed by two authors and a research assistant (NW, HJ and Sharina Riva), with 20% cross-checked by Sharina Riva. Eight studies received a low risk of bias, 13 suggested some concerns and 2 had a high risk of bias (figure 2). Risk of bias was not completed for one study as it was a pilot study where the waitlist data were collected from participants 2 months prior to the delivery of the intervention.<sup>30</sup> The same participants were then treated as the intervention group.

## RESULTS

### Study characteristics

Of 6440 articles screened, 24 were included in the review (figure 1), totalling 2015 participants. The majority of studies were published in the USA (12/24, 50%) and two-thirds were randomised controlled trials (16/24, 67%). Nearly all studies focused on spousal carers as participants (22/24, 92%) and just under half were conducted in a face-to-face setting (11/24, 46%). On average, women accounted for 97% of participants (range 40%–100%, SD 14). Most interventions were delivered as a patient–carer dyad as opposed to solely focusing on carers (22/24, 92%). Recruitment rates were on average 35% across studies (range 26%–98%, SD 22). See online supplemental table 1 for full study demographics.

### Intervention modality

Overall, 10 of 24 studies (42%) delivered their intervention solely face to face,<sup>30–39</sup> of these 7 showed a significant impact on carers' outcomes<sup>30–35 37 39</sup> (see online supplemental table 2). Nine studies delivered interventions using a combination of modalities<sup>27 40–47</sup> and six had a significant impact on carers' outcomes.<sup>27 40 41 43 45</sup> Two studies trialled telephone interventions,<sup>48 49</sup> one of which had a significant impact on carers' outcomes.<sup>48</sup> Two studies used online interventions,<sup>50 51</sup> one of which showed a significant impact on outcomes.<sup>51</sup>

### Intervention description

Interventions focused on a variety of topics, with some using multiple approaches. This included counselling therapies,<sup>24 27 31–33 36 38–45 48 52</sup> skills training,<sup>49</sup> information booklets or online modules,<sup>40 46–48 50 51</sup> information sessions<sup>30 35</sup> and exercise.<sup>34 37 41</sup> The majority of interventions (19/24, 74%) were presented as weekly modules<sup>27 31–37 39–42 44–46 48 49 51 52</sup> that were most frequently 6 (n=6/24, 25%)<sup>33 35 40 42 49 52</sup> or 8 weeks in duration (n=5/24, 17%).<sup>27 36 39 45 48</sup> Intervention content was tailored to family members

Study	Risk of bias domains					Overall
	D1	D2	D3	D4	D5	
Badger, et al. 2011 [48]	+	+	+	+	+	+
Borji, et al. 2017 [31]	-	X	+	+	+	X
Campbell, et al. 2007 [49]	-	+	+	+	+	+
Canada, et al. 2005 [32]	+	-	+	+	+	-
Carlson, et al. 2017 [52]	+	-	+	+	+	-
Chambers, et al. 2015 & 2019 [27, 28]	+	+	+	+	+	+
Chien, et al. 2020 [40]	+	+	+	+	+	+
Couper, et al. 2015 [33]	+	+	+	+	+	+
Karlsen, et al. 2021 [41]	+	+	+	+	+	+
Karlsen, et al. 2017 [42]	X	X	X	X	+	X
Levesque, et al. 2015 [47]	-	+	+	+	+	-
Lyons, et al. 2016 [34]	-	+	+	+	+	-
Malcarne, et al. 2019 [39]	-	+	+	+	+	-
Manne, et al. 2004 [35]	-	+	+	+	+	-
Manne, et al. 2019 [43]	-	+	+	+	+	-
Manne, et al. 2011 [36]	-	+	+	+	+	-
McCaughan, et al. 2018 [44]	+	+	+	+	+	+
Northouse, et al. 2007 [45]	-	+	+	+	+	-
Robertson, et al. 2016 [38]	+	+	+	+	+	+
Song, et al. 2021 [50]	-	+	+	+	+	-
Walker, et al. 2013 [46]	-	+	+	+	+	-
Wittmann, et al. 2022 [51]	-	+	+	+	+	-
Winters-Stone, et al. 2016 [37]	+	+	+	-	+	-

Domains:  
D1: Bias arising from the randomization process.  
D2: Bias due to deviations from intended intervention.  
D3: Bias due to missing outcome data.  
D4: Bias in measurement of the outcome.  
D5: Bias in selection of the reported result.

Judgement  
X High  
- Some concerns  
+ Low

Figure 2 Risk of bias.

supportive care needs in the majority of studies (19/24, 79%).<sup>30-33 36-43 45 48-52</sup>

#### Randomised controlled trials (16/24)

Two-thirds of the studies were randomised control trials (16/24, 67%). Of these, seven studies used a combination of modalities including face to face, telephone, online, hardcopy material and other multimedia formats, with intervention periods ranging from 2 to 24 weeks.<sup>27 39-41 43-46</sup> Face-to-face interventions were trialled across five studies with intervention periods ranging from 5 to 26 weeks.<sup>31 33-35 37</sup> Two studies used telephone interventions with intervention periods ranging from 6 to 8 weeks,<sup>48 49</sup> and one used an online intervention with a 28-week period.<sup>51</sup>

#### Pilot studies (8/24)

Half of the pilot studies assessed face-to-face interventions (4/8, 50%); and only two studies measured duration ranging from 4 to 8 weeks.<sup>32 36</sup> Two studies used a combination of approaches including face to face, hardcopy material and multimedia formats, of these one was a 6-week course<sup>42</sup> and one provided material to participants at baseline which was then accessed on an 'as needs' basis by participants.<sup>47</sup> One study assessed an online intervention which was accessed on an 'as needs' basis by participants<sup>50</sup> and one study held group sessions over a 6-week period; however, the mode of delivery of the groups was not specified.<sup>52</sup>

## Impact of interventions on carer outcomes

A total of 15 studies (63%) reported a significant impact on carer outcomes. Of these, 13 were RCTs,<sup>27 31 33–35 37 39–41 43 45 48 51</sup> n=5 had a low risk of bias<sup>27 33 40 41 48</sup> and n=6 were scored as ‘some concerns’ due to lack of clear reporting during randomisation.<sup>34 35 39 43 45</sup> Two were pilot studies that have significant impacts on carers’ outcomes, one raised concerns about interventions concealment<sup>32</sup> and one was not assessed for bias.<sup>30</sup> Six studies had no impact on carers’ outcomes; one RCT<sup>44</sup> and five pilot studies,<sup>38 42 47 50 52</sup> of these only two had a low risk of bias.<sup>38 44</sup> See online supplemental table 2 for a full description.

Of the 15 studies that had an improvement in outcomes, 12 (80%) tailored their content to family members’ supportive needs.<sup>30–33 37 39–41 43 45 48 51</sup> Six studies (25%) found that their intervention had no impact on family members’ outcomes,<sup>38 42 44 47 50 52</sup> of these six, five (83%) presented intervention content tailored to family members’ supportive care needs.<sup>38 42–44 50 52</sup>

## Significant findings

During at least one time point in each study, the RCTs showed significant improvements in a range of outcomes including depression,<sup>31 48</sup> anxiety,<sup>31</sup> fatigue, social well-being, social support from family, spiritual well-being,<sup>48</sup> relationship satisfaction,<sup>27 43</sup> positive and negative affect,<sup>40</sup> distress,<sup>39</sup> cohesion, avoidance and conflict resolution,<sup>33</sup> affectionate behaviours,<sup>34</sup> sexual functioning,<sup>27 51</sup> higher sexual satisfaction, intimacy and fewer sexual unmet needs,<sup>27</sup> dyadic adjustment, problem-solving,<sup>39</sup> subsections of coping,<sup>35</sup> subsections of post-traumatic growth,<sup>35 43</sup> higher quality of life communication, active communication and self-efficacy, and lower negative appraisal, uncertainty, symptom distress, problems with husband’s incontinence and hopelessness,<sup>45</sup> lean mass, upper and lower body strength and chair standing time<sup>37</sup> and general physical function.<sup>41</sup> Pilot studies showed significant improvements in female sexual functioning<sup>30 32</sup> medical impact, sexual interest and problems.<sup>30</sup>

Two RCTs measured effect sizes and found moderate effect sizes for depression, fatigue, vigour<sup>49</sup> dyadic adjustment and intimacy in relationships.<sup>46</sup> One pilot study found moderator effects for baseline cancer specific distress, relationship satisfaction and intimacy.<sup>36</sup>

## Intervention focus categorised into common supportive care needs

In 10 studies (42%), the primary area of focus of each study often spanned multiple supportive care needs<sup>27 36–38 40 43–46 49</sup> (see online supplemental table 2). The most common outcomes were psychological (14/24, 58%),<sup>31 35–40 43–45 48–50 52</sup> sexual (10/24, 42%)<sup>27 30 32 34 38 40–42 46 51</sup> and informational (6/24, 25%).<sup>40 44–47 49</sup> One quarter of studies included additional measures including symptom management,

quality of life, health related quality of life and a broader unmet supportive care needs measurement.

Eight RCTs had a low risk of bias<sup>27 33 40 41 44 48 49</sup> and eight raised some concerns.<sup>31 34 35 39 43 45 46 51</sup> Of these, lack of clear reporting of the randomisation process raised some concerns in n=7,<sup>34 35 39 43 45 46 51</sup> and a high risk of bias occurred in one study n=1 as there was no record of an analysis plan and the appropriateness of results could not be assessed.<sup>31</sup> Across pilot studies, n=1 had a low risk of bias<sup>38</sup> and n=6 raised some concerns.<sup>32 36 42 47 50 52</sup> Of these, n=3 did not clearly report on randomisation procedure.<sup>36 47 50</sup> In two studies, there was little information given about concealment of assigned intervention prior to randomisation, due to the nature of interventions, for example, counselling, there was potential for bias to occur in as a result of knowledge of the intervention.<sup>32 52</sup> One study had a high risk of bias across multiple domains.<sup>42</sup>

## DISCUSSION

In this review, we found that the majority of interventions available to carers of men with prostate cancer were provided in face-to-face format, delivered a counselling intervention and focused on spouses. Half of the included studies showed a significant impact on a variety of carers’ outcomes. Of these studies, three-quarters provided some elements of tailoring content to carers’ own circumstances. Studies largely focused on psychological, sexual and informational aspects of caregiving.

There is debate around the ideal delivery modality of interventions for carers of people with cancer. In this review, earlier studies used a combination of approaches including face to face, written material, CD-ROMs and early technology such as the telephone; later studies primarily using face-to-face approaches with few using online only interventions. However, our findings contrast the cultural shift in the delivery of interventions to digital health platforms.<sup>53</sup> Our results indicate that a higher number of face-to-face interventions provided positive outcomes for carers. It is possible that face-to-face settings correspond with the type of supportive care needs identified in this review such as psychological and sexual needs. These types of needs may often be addressed through counselling interventions requiring needs assessment of individuals’ and couples traditionally conducted in a face-to-face setting. However, previous research has identified that technology-based interventions show promising results<sup>54</sup> for education, cognitive therapies, communication and support. Further research is required into the use of innovative solutions such as video conferencing and telehealth in supporting counselling-based services for people affected by prostate cancer to support traditional face-to-face services. In addition to existing face-to-face interventions, greater understanding and use of innovative resources will allow for the delivery of interventions to carers

where none existed before, for example, in rural and regional areas.

Despite our findings of the success of face-to-face interventions, it is important to recognise the context of the COVID-19 pandemic and lockdowns worldwide where family members have been unable to attend outpatient settings with patients. The long-term ramifications on carers' support needs and well-being are yet known. The adaptation of resources, including face to face and digital options, may allow for carers in diverse circumstances to seek support. There is a need for flexibility in the delivery of services. Recruitment rates of the included studies were low (average 35%), indicating that carers are unlikely to volunteer or initiate participation in programmes, as well as highlighting challenges in recruiting patient–carer dyads into research projects. These findings are similar across other studies.<sup>55 56</sup> Reasons for hesitancy to seek support include lack of time for themselves, not acknowledging their own needs or having limited time to participate in additional tasks.<sup>13</sup> There is a need therefore to embed new services into existing healthcare structures with automatic referrals to ensure uptake of programmes.<sup>57</sup> Support for and referral into interventions have the potential to promote health and well-being during the illness and caring period, and more can be done to intervene early prior to unmet needs developing. A hybrid model of care may be required following the pandemic period; however, what this looks like in the long term and how sustainable it is requires further investigation.

The impact of interventions addressing couples' needs has been explored previously and found that couples' based interventions are as successful as stand-alone patient and carer interventions.<sup>58</sup> Despite positive impacts of couples based interventions, a more recent review has identified that couple-based interventions are inadequate in addressing and producing successful outcomes for both patients and partners simultaneously.<sup>24</sup> There is a need to tailored content to address the needs of family members<sup>59</sup>; however, in this review we found that nearly equal amounts of studies with tailored content to family members' needs both had a significant improvement in outcomes (n=10) or had no improvement in outcomes (n=7). One reason for this may be the level of tailoring provided to carers. Interventions were largely dyad based and at times were tailored to couples' needs rather than individuals' needs. While many dyads affected by prostate cancer experience unmet needs as a couple, there may be individual supportive care needs that carers experience, such as, dealing with emotions related to cancer,<sup>60</sup> and at times planning for life after death.<sup>61</sup> There is a need to ensure that future interventions incorporate less common unmet needs experienced by cancer carers to meet the needs of the carer.<sup>62</sup> Additionally, while it was not represented in this review, the male/female spouse dyad represents only one patient–carer relationship

who experience prostate cancer. Previous research indicates that up to 19% of carers of people with prostate cancer may also be children, or other relatives or friends<sup>63</sup> where sexual and marital unmet needs may not be relevant for the carer. Similarly in this study, we found that couples were predominately heterosexual with women, representing 97% of the sample. This limits the ability to assess whether success of interventions is related to carers' gender. It is known that women both living with cancer<sup>64</sup> and who are carers<sup>65 66</sup> experience higher levels of distress compare to people who do not identify as woman. Given that dyad interventions comprise primarily heterosexual spousal,<sup>67</sup> there is a pressing need to codesign and evaluate interventions for same-sex couples, or those who have a different relationship with the person living with prostate cancer to ensure that interventions are inclusive and encompassing to the needs of the caring population. The use of tailoring across flexible technology-based platforms requires further exploration to assess whether one programme can address both dyadic and individual needs for carers from diverse situations.

Consideration should be taken when designing and implementing studies about the language used as many carers do not identify with the term 'carer'.<sup>68</sup> In day-to-day practice, conversations between clinicians and patients/carers should include defining whether the patient has a carer or support person, and the term they prefer to use when being addressed.<sup>69</sup>

From this review, we identified that interventions were largely focused on psychological, sexual and informational outcomes. However, carers of people with prostate cancer also experience other gaps in care, including the need for peer support,<sup>70</sup> and practical advice related to everyday care needs.<sup>18 70</sup> This highlights gaps in prostate cancer research and the need for interventions for carers own needs during the disease trajectory. Interventions had an impact on a diverse range of outcomes including psychological, social, marital and physical well-being, suggesting that interventions have the potential to meet the complex needs that carers experience. However, more research is needed to explore whether the focus of interventions can be broadened to meet a variety of needs experienced by carers and whether any resulting impact on outcomes can be seen. The majority of studies (60%) demonstrated that interventions had a significant impact on carers' outcomes; however, this was across a multitude of psychological, physical and interpersonal measurements. Greater understanding of how interventions can improve carers' well-being in the short-term and long term is needed.<sup>48</sup>

#### Limitations

One limitation of this work is the lack of information provided about the stage of mens' illness or the treatment they were undertaking, due to the heterogeneity of information reported this information was

unable to be extracted. Carers can experience different supportive care needs in relation to the stage of diagnosis and treatment type. Further work should clearly report on the patients stage of illness in order to ascertain the impact on the carer at that time.

Findings of this review are limited as the majority of studies (63%) had 'some concerns' or high risk of bias.

In the majority of cases, this was due to inadequate reporting of randomisation and concealment, this is similar across risk of bias findings in other similar systematic reviews.<sup>71</sup> However, as only five of the studies included had a low risk of bias and significant impact on outcomes, findings should be interpreted with caution. Future research is needed to strengthen findings, and clearer reporting is required to accurately determine risk of bias.

## CONCLUSIONS

Our review highlighted that interventions for carers of people with cancer were largely face to face, were counselling based and patient–spouse focused. Most interventions addressed psychological, sexual and informational unmet needs. Opportunities exist for flexible technology-based interventions to test tailored programmes addressing complex unmet needs meeting dyad and individual carer needs. Findings from these interventions may provide additional information about the success of interventions in improving outcomes of carers of people with prostate cancer.

**Acknowledgements** The authors also wish to acknowledge Sharina Riva, Deakin University, for her research assistance support.

**Contributors** All authors contributed to the study concept and design. HJ performed the literature search. NW and HJ screened resources. Data was extracted by NW, AU and HJ and cross-checked by NW. Data synthesis was performed by NW. The first draft of the manuscript was written by NW and HJ. All authors critically revised and approved of the final manuscript. NW is the gaurantor who accepts full responsibility for the finished work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient consent for publication** Not applicable.

**Ethics approval** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as online supplemental information.

**Supplemental material** This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of

the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

**ORCID iD**

Natalie Winter <http://orcid.org/0000-0002-1847-6862>

## REFERENCES

- 1 Australian Institute of Health and Welfare. *Cancer in Australia 2019*. Canberra: AIHW, 2019.
- 2 Chism K, Kunkel EJS. Prostate cancer: issues in psychosomatic medicine. *Curr Psychiatry Rep* 2009;11:205–10.
- 3 Davis-Ali SH, Chesler MA, Chesney BK. Recognizing cancer as a family disease: worries and support reported by patients and spouses. *Soc Work Health Care* 1993;19:45–65.
- 4 Ockerby C, Livingston P, O'Connell B, *et al*. The role of informal Caregivers during cancer patients' recovery from chemotherapy. *Scand J Caring Sci* 2013;27:147–55.
- 5 Vasileiou K, Barnett J, Barreto M, *et al*. Experiences of loneliness associated with being an informal Caregiver: A qualitative investigation. *Front Psychol* 2017;8:585.
- 6 Piervil E, Odedina F, Young ME. The role and influence of prostate cancer Caregivers across the care continuum. *Health Promot Pract* 2019;20:436–44.
- 7 Lambert SD, Hulbert-Williams N, Belzile E, *et al*. Beyond using composite measures to analyze the effect of unmet supportive care needs on Caregivers' anxiety and depression. *Psychooncology* 2018;27:1572–9.
- 8 Elliott S, Latini DM, Walker LM, *et al*. Androgen deprivation therapy for prostate cancer: recommendations to improve patient and partner quality of life. *The Journal of Sexual Medicine* 2010;7:2996–3010.
- 9 Wassersug RJ. Maintaining intimacy for prostate cancer patients on androgen deprivation therapy. *Curr Opin Support Palliat Care* 2016;10:55–65.
- 10 Donovan KA, Walker LM, Wassersug RJ, *et al*. Psychological effects of androgen-deprivation therapy on men with prostate cancer and their partners. *Cancer* 2015;121:4286–99.
- 11 Nolsøe AB, Jensen CFS, Østergren PB, *et al*. Neglected side effects to curative prostate cancer treatments. *Int J Impot Res* 2021;33:428–38.
- 12 Heynsbergh N, Botti M, Heckel L, *et al*. Caring for the person with cancer: information and support needs and the role of technology. *Psychooncology* 2018;27:1650–5.
- 13 Heynsbergh N, Botti M, Heckel L, *et al*. Caring for the person with cancer and the role of Digital technology in supporting Carers. *Support Care Cancer* 2019;27:2203–9.
- 14 Burns CM, Dixon T, Smith WT, *et al*. Patients with advanced cancer and family Caregivers' knowledge of health and community services: a longitudinal study. *Health Soc Care Community* 2004;12:488–503.
- 15 Ogah I, Wassersug RJ. How reliable are "reputable sources" for medical information on the Internet? the case of hormonal therapy to treat prostate cancer. *Urol Oncol* 2013;31:1546–52.
- 16 Australian Commission on Safety and Quality in Health Care (ACSQHC). *Health literacy – A summary for consumers, A.C.o.S.A.Q.i.H.* Sydney: Care, 2015.
- 17 Elliott (nee Murray) K-EJ, Scott JL, Monsour M, *et al*. Profiles of Dyadic adjustment for advanced prostate cancer



- to inform couple-based intervention. *Psychology & Health* 2015;30:1259–73.
- 18 Green A, Winter N, DiGiacomo M, *et al.* Experiences of female partners of prostate cancer survivors: A systematic review and thematic synthesis. *Health Soc Care Community* 2022;30:1213–32.
  - 19 Wibowo E, Wassersug RJ, Robinson JW, *et al.* An educational program to help patients manage androgen deprivation therapy side effects: feasibility, acceptability, and preliminary outcomes. *Am J Mens Health* 2020;14:1557988319898991.
  - 20 Paich K, Dunn R, Skolarus T, *et al.* Preparing patients and partners for recovery from the side effects of prostate cancer surgery: A group approach. *Urology* 2016;88:36–42.
  - 21 Bobridge A, Bond MJ, Marshall V, *et al.* An investigation of the support needs of men and partners throughout the prostate cancer journey. *Psychooncology* 2015;24:341–7.
  - 22 Evertsen JM, Wolkenstein AS. Female partners of patients after surgical prostate cancer treatment: interactions with physicians and support needs. *BMC Fam Pract* 2010;11:19.
  - 23 Northouse LL, Katapodi MC, Song L, *et al.* Interventions with family Caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin* 2010;60:317–39.
  - 24 Chambers SK, Hyde MK, Smith DP, *et al.* New challenges in psycho-oncology research III: A systematic review of psychological interventions for prostate cancer survivors and their partners: clinical and research implications. *Psychooncology* 2017;26:873–913.
  - 25 Wootten AC, Abbott JM, Farrell A, *et al.* Psychosocial interventions to support partners of men with prostate cancer: a systematic and critical review of the literature. *J Cancer Surviv* 2014;8:472–84.
  - 26 Schardt C, Adams MB, Owens T, *et al.* Utilization of the PICO framework to improve searching PubMed for clinical questions. *BMC Med Inform Decis Mak* 2007;7:16.
  - 27 Chambers SK, Occhipinti S, Stiller A, *et al.* Five-year outcomes from a randomised controlled trial of a couples-based intervention for men with Localised prostate cancer. *Psychooncology* 2019;28:775–83.
  - 28 Chambers SK, Occhipinti S, Schover L, *et al.* A randomised controlled trial of a couples-based sexuality intervention for men with Localised prostate cancer and their female partners. *Psychooncology* 2015;24:748–56.
  - 29 Campbell M, McKenzie JE, Sowden A, *et al.* Synthesis without meta-analysis (swim) in systematic reviews: reporting guideline. *BMJ* 2020;368:l6890.
  - 30 Hampton AJD, Walker LM, Beck A, *et al.* A brief couples' workshop for improving sexual experiences after prostate cancer treatment: a feasibility study. *Support Care Cancer* 2013;21:3403–9.
  - 31 Borji M, Nourmohammadi H, Otaghi M, *et al.* Positive effects of cognitive behavioral therapy on depression, anxiety and stress of family Caregivers of patients with prostate cancer: A randomized clinical trial. *Asian Pac J Cancer Prev* 2017;18:3207–12.
  - 32 Canada AL, Neese LE, Sui D, *et al.* Pilot intervention to enhance sexual rehabilitation for couples after treatment for localized prostate carcinoma. *Cancer* 2005;104:2689–700.
  - 33 Couper J, Collins A, Bloch S, *et al.* Cognitive existential couple therapy (CECT) in men and partners facing Localised prostate cancer: a randomised controlled trial. *BJU Int* 2015;115 Suppl 5:35–45.
  - 34 Lyons KS, Winters-Stone KM, Bennett JA, *et al.* The effects of partnered exercise on physical intimacy in couples coping with prostate cancer. *Health Psychol* 2016;35:509–13.
  - 35 Manne S, Babb J, Pinover W, *et al.* Psychoeducational group intervention for Wives of men with prostate cancer. *Psychooncology* 2004;13:37–46.
  - 36 Manne SL, Kissane DW, Nelson CJ, *et al.* Intimacy-enhancing psychological intervention for men diagnosed with prostate cancer and their partners: a pilot study. *J Sex Med* 2011;8:1197–209.
  - 37 Winters-Stone KM, Lyons KS, Dobek J, *et al.* Benefits of partnered strength training for prostate cancer survivors and spouses: results from a randomized controlled trial of the exercising together project. *J Cancer Surviv* 2016;10:633–44.
  - 38 Robertson J, McNamee P, Molloy G, *et al.* Couple-based Psychosexual support following prostate cancer surgery: results of a feasibility pilot randomized control trial. *J Sex Med* 2016;13:1233–42.
  - 39 Malcarne VL, Ko CM, Roesch SC, *et al.* Efficacy of problem-solving therapy for spouses of men with prostate cancer: A randomized controlled trial. *Psychooncology* 2019;28:497–504.
  - 40 Chien C-H, Chung H-J, Liu K-L, *et al.* Effectiveness of a couple-based Psychosocial intervention on patients with prostate cancer and their partners: A quasi-experimental study. *J Adv Nurs* 2020;76:2572–85.
  - 41 Karlsen RV, Bidstrup PE, Giraldo A, *et al.* Couple counseling and pelvic floor muscle training for men operated for prostate cancer and for their female partners: results from the randomized Procan trial. *Sex Med* 2021;9:100350.
  - 42 Karlsen RV, E. Bidstrup P, Hvarness H, *et al.* Feasibility and acceptability of couple counselling and pelvic floor muscle training after operation for prostate cancer. *Acta Oncologica* 2017;56:270–7.
  - 43 Manne SL, Kashy DA, Zaider T, *et al.* Couple-focused interventions for men with localized prostate cancer and their spouses: A randomized clinical trial. *Br J Health Psychol* 2019;24:396–418.
  - 44 McCaughan E, Curran C, Northouse L, *et al.* Evaluating a Psychosocial intervention for men with prostate cancer and their partners: outcomes and lessons learned from a randomized controlled trial. *Appl Nurs Res* 2018;40:143–51.
  - 45 Northouse LL, Mood DW, Schafenacker A, *et al.* Randomized clinical trial of a family intervention for prostate cancer patients and their spouses. *Cancer* 2007;110:2809–18.
  - 46 Walker LM, Hampton AJ, Wassersug RJ, *et al.* Androgen deprivation therapy and maintenance of intimacy: a randomized controlled pilot study of an educational intervention for patients and their partners. *Contemp Clin Trials* 2013;34:227–31.
  - 47 Levesque JV, Lambert SD, Girgis A, *et al.* Do men with prostate cancer and their partners receive the information they need for optimal illness self-management in the immediate post-diagnostic phase? *Asia Pac J Oncol Nurs* 2015;2:169–75.
  - 48 Badger TA, Segrin C, Figueredo AJ, *et al.* Psychosocial interventions to improve quality of life in prostate cancer survivors and their intimate or family partners. *Qual Life Res* 2011;20:833–44.
  - 49 Campbell LC, Keefe FJ, Scipio C, *et al.* Facilitating research participation and improving quality of life for African American prostate cancer survivors and their intimate partners. A pilot study of telephone-based coping skills training. *Cancer* 2007;109(2 Suppl):414–24.
  - 50 Song L, Guo P, Tan X, *et al.* Enhancing survivorship care planning for patients with localized prostate cancer using a couple-focused web-based, mHealth program: the results of a pilot feasibility study. *J Cancer Surviv* 2021;15:99–108.
  - 51 Wittmann D, Mehta A, Bober SL, *et al.* Truenth sexual recovery intervention for couples coping with prostate cancer: randomized controlled trial results. *Cancer* 2022;128:1513–22.
  - 52 Carlson LE, Rouleau CR, Specia M, *et al.* Brief supportive-expressive group therapy for partners of men with early stage prostate cancer: lessons learned from a negative randomized controlled trial. *Support Care Cancer* 2017;25:1035–41.
  - 53 Meskó B, Drobni Z, Bényei É, *et al.* Digital health is a cultural transformation of traditional Healthcare. *Mhealth* 2017;3:38.

- 54 Department of Health. *Cancer Australia, Cancer support organisations*. Government of Australia: Australia, 2022.
- 55 Heckel L, Gunn KM, Livingston PM. The challenges of recruiting cancer patient/Caregiver Dyads: informing randomized controlled trials. *BMC Med Res Methodol* 2018;18:146.
- 56 Molassiotis A, Brown T, Cheng HL, *et al*. The effects of a family-centered Psychosocial-based nutrition intervention in patients with advanced cancer: the Picnic2 pilot randomised controlled trial. *Nutr J* 2021;20:2.
- 57 Ugalde A, Winter N, Sansom-Daly UM, *et al*. Effective integration of Caregivers and families as part of the care team for people with cancer. *Aust J Gen Pract* 2021;50:527–31.
- 58 Regan TW, Lambert SD, Girgis A, *et al*. Do couple-based interventions make a difference for couples affected by cancer? A systematic review. *BMC Cancer* 2012;12:279.
- 59 Heynsbergh N, Heckel L, Botti M, *et al*. Feasibility, Useability and acceptability of technology-based interventions for informal cancer Carers: a systematic review. *BMC Cancer* 2018;18:244.
- 60 Ervik B, Nordøy T, Asplund K. In the middle and on the sideline: the experience of spouses of men with prostate cancer. *Cancer Nurs* 2013;36:E7–14.
- 61 Hawes SM, Malcarne VL, Ko CM, *et al*. Identifying problems faced by spouses and partners of patients with prostate cancer. *Oncology Nursing Forum* 2006;33:807–14.
- 62 Lambert SD, Girgis A. Unmet supportive care needs among informal Caregivers of patients with cancer: opportunities and challenges in informing the development of interventions. *Asia Pac J Oncol Nurs* 2017;4:136–9.
- 63 Cal A, Zengin S, Avci IA. Needs of patients with prostate cancer for home care. *Asia Pac J Oncol Nurs* 2018;5:408–14.
- 64 Carlson LE, Zelinski EL, Toivonen KI, *et al*. Prevalence of Psychosocial distress in cancer patients across 55 North American cancer centers. *J Psychosoc Oncol* 2019;37:5–21.
- 65 Ketcher D, Trettevik R, Vadaparampil ST, *et al*. Caring for a spouse with advanced cancer: similarities and differences for male and female Caregivers. *J Behav Med* 2020;43:817–28.
- 66 Hedden L, Wassersug R, Mahovlich S, *et al*. Evaluating an educational intervention to alleviate distress amongst men with newly diagnosed prostate cancer and their partners. *BJU Int* 2017;120:E21–9.
- 67 Coyne E, Heynsbergh N, Dieperink KB. Acknowledging cancer as a family disease: A systematic review of family care in the cancer setting. *Eur J Oncol Nurs* 2020;49:101841.
- 68 Ugalde A, Krishnasamy M, Schofield P. Role recognition and changes to self-identity in family Caregivers of people with advanced cancer: a qualitative study. *Support Care Cancer* 2012;20:1175–81.
- 69 McGillivray HMK, Piccolo EEL, Wassersug RJ. Caregiver", or "Co-Survivor"—Might the label we give the partners of cancer patients affect the health outcome of the patients and their partners *Current Oncology* 2022;29:122–9.
- 70 Winter N, Green A, Jongebloed H, *et al*. Designing supportive E-interventions for partners of men with prostate cancer using female partners' experiences: qualitative exploration study. *JMIR Cancer* 2022;8:e31218.
- 71 Park CL, Pustejovsky JE, Trevino K, *et al*. Effects of Psychosocial interventions on meaning and purpose in adults with cancer: A systematic review and meta-analysis. *Cancer* 2019;125:2383–93.