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Full References:

Webb, K., Sharpe, L., Russell, H., & Shaw, J. (2023). The CARE-FCR: Development and validation of a caregiver-specific measure of fear of cancer recurrence and progression. Poster presentation, Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting, 1-3rd Nov, Melbourne, Victoria, Australia

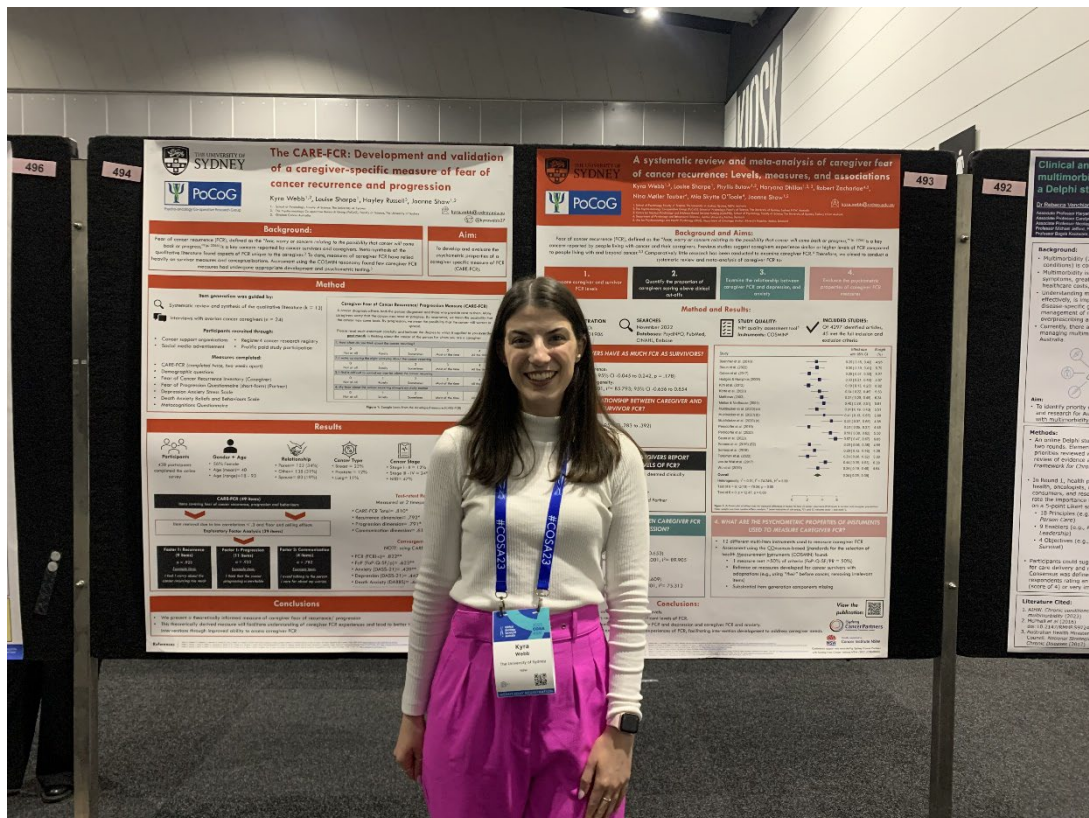
Webb, K., Sharpe, L., Butow, P., Dhillon, H., Zachariae, R., Tauber, N. M., O'Toole, M. S., & Shaw, J. (2023). A systematic review and meta-analysis of caregiver fear of cancer recurrence: Levels, measures, and associations. Poster presentation, Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting, 1-3rd Nov, Melbourne, Victoria, Australia.

Conference: Clinical Oncology Society of Australia, Annual Scientific Meeting (COSA ASM)

Location: Melbourne, Victoria, Australia

Dates: 1 – 3rd November 2023

Presentation Type: Poster



Kyra Webb with both of her posters at the Clinical Oncology Society of Australia’s Annual Scientific Meeting (COSA ASM), held in Melbourne, Victoria, 1st – 3rd November 2023. Posters detail findings from a study conducted to develop and validate a caregiver-specific measure of fear of cancer recurrence (CARE-FCR), and a systematic review and meta-analysis to quantify caregiver levels of fear of cancer recurrence across studies.

I had the opportunity to attend the 2023 Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting, held at the Melbourne Convention and Exhibition Centre in Victoria, Australia.

The theme this year was *50 years of innovation in cancer care: Learning from the past to inspire the future*. The conference demonstrated a strong focus on breast and gynaecological cancers. COSA features a multi-disciplinary membership, conference delegates included clinicians and researchers working in various areas which was reflected in the breadth of presentation topics covered across the course of the conference.

A session highlight was the *'using a multi-disciplinary approach to customise models of cancer care'* session on Wednesday, which detailed the importance of shared care and the role of multi-disciplinary teams working together. The session also featured an inspiring consumer presentation which captured the experiences of navigating cancer care and the value of personalised care. Additionally, this presentation also highlighted the importance of informal care and support provided through friends and family members across the course of the cancer trajectory.

Attendance at this conference provided the opportunity to network with other clinicians and researchers working within the area. These conversations were highly valuable and provided the chance to consider the implications of my research more broadly, which has been especially beneficial as I near the end of my PhD candidature. Presenting findings from across the course of my project also provided the opportunity to reflect on the project as a whole, highlighting how each of the findings have informed the direction of the subsequent studies. I also enjoyed speaking with the conference exhibitors and learning about the difference resources that are available to support people living with and beyond cancer and their family members. Through these conversations the importance of informal care and support networks was highlighted, and discussions centred around how we can better support partners, friends, and family members. Learnings from this conference will help guide future directions as I consider post-PhD career opportunities and possible further research, with the aim of supporting people who provide care.

Thank you to Sydney Cancer Partners for the funding received to support travel and attendance at this conference. I really enjoyed my time and was excited to present two posters, meet new people working within the area and learn about new and emerging research being conducted.

The CARE-FCR: Development and validation of a caregiver-specific measure of fear of cancer recurrence and progression

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Background:

Fear of cancer recurrence (FCR), defined as the “fear, worry or concern relating to the possibility that cancer will come back or progress,”¹ (p. 3266) is a key concern reported by cancer survivors and caregivers. Meta-synthesis of the qualitative literature found aspects of FCR unique to the caregiver.² To date, measures of caregiver FCR have relied heavily on survivor measures and conceptualisations. Assessment using the COSMIN taxonomy found few caregiver FCR measures had undergone appropriate development and psychometric testing.³

Aim:

To develop and evaluate the psychometric properties of a caregiver specific measure of FCR (CARE-FCR).

Method

Item generation was guided by:

- Systematic review and synthesis of the qualitative literature (k = 13)
- Interviews with ovarian cancer caregivers (n = 24)

Participants recruited through:

- Cancer support organisations
- Register4 cancer research registry
- Social media advertisement
- Prolific paid study participation

Measures completed:

- CARE-FCR (completed twice, two weeks apart)
- Demographic questions
- Fear of Cancer Recurrence Inventory (Caregiver)
- Fear of Progression Questionnaire (short-form) (Partner)
- Depression Anxiety Stress Scale
- Death Anxiety Beliefs and Behaviours Scale
- Metacognitions Questionnaire

Caregiver Fear of Cancer Recurrence/ Progression Measure (CARE-FCR)

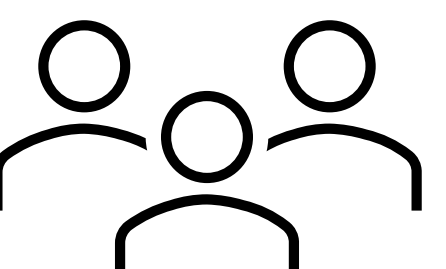
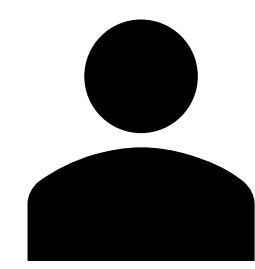

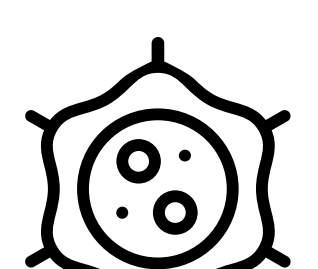

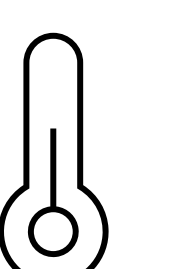
A cancer diagnosis affects both the person diagnosed and those who provide care to them. Many caregivers worry that the cancer may recur or progress. By recurrence, we mean the possibility that the cancer may come back. By progression, we mean the possibility that the cancer will worsen or spread.

Please read each statement carefully and indicate the degree to which it applied to you **over the past month** in thinking about the cancer of the person for whom you are a caregiver.

Item	0	1	2	3	4
1. How often do you think about the cancer recurring?	Not at all	Rarely	Sometimes	Most of the time	All the time
2. I wake up during the night worrying about the cancer recurring	Not at all	Rarely	Sometimes	Most of the time	All the time
3. I find it difficult to control my worries about the cancer recurring	Not at all	Rarely	Sometimes	Most of the time	All the time
4. My fear about the cancer recurring disrupts my daily routine	Not at all	Rarely	Sometimes	Most of the time	All the time

Figure 1: Sample items from the developed measure (CARE-FCR)

Results

 <p>Participants 438 participants completed the online survey</p>	 <p>Gender + Age • 56% Female • Age (mean)= 40 • Age (range)=18 - 93</p>	 <p>Relationship • Parent= 152 (34%) • Other= 135 (31%) • Spouse= 83 (19%)</p>	 <p>Cancer Type • Breast = 23% • Prostate = 12% • Lung = 11%</p>	 <p>Cancer Stage • Stage I - II = 12% • Stage III - IV = 24% • NED= 47%</p>	 <p>Clinical FCR Levels 40% of caregivers reported clinical levels using the FCRI cut-off</p>
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CARE-FCR (49 items)

Items covering fear of cancer recurrence, progression and behaviours

Item removal due to low correlations < .3 and floor and ceiling effects

Exploratory Factor Analysis (29 items)

Factor 1: Recurrence (9 items)

$\alpha = .923$

Example item:

I feel I worry about the cancer recurring too much

Factor 1: Progression (11 items)

$\alpha = .933$

Example item:

I think that the cancer progressing is inevitable

Factor 3: Communication (4 items)

$\alpha = .782$

Example item:

I avoid talking to the person I care for about my worries

Test-retest Reliability

Measured at 2 timepoints 2 weeks apart

- CARE-FCR Total= .810*
- Recurrence dimension= .792*
- Progression dimension= .791*
- Communication dimension= .616*

Convergent Validity

NOTE: using CARE-FCR total scores

- FCR (FCRI-c)= .822**
- FoP (FoP-Q-SF/p)= .623**
- Anxiety (DASS-21)= .439**
- Depression (DASS-21)= .442**
- Death Anxiety (DABBS)= .440**

** Correlation is significant at the .01 level (2-tailed)

Conclusions

- We present a theoretically informed measure of caregiver fear of recurrence/ progression
- This theoretically derived measure will facilitate understanding of caregiver FCR experiences and lead to better targeted interventions through improved ability to assess caregiver FCR

References

- Lebel, S., Ozakinci, G., Humphris, G., Mutsaers, B., Thewes, B., Prins, J., Dinkel, A., & Butow, P. (2016). From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Supportive care in cancer*, 24(8), 3265-3268. <https://doi.org/10.1007/s00520-016-3272-5>
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Background and Aims:

Fear of cancer recurrence (FCR), defined as the “fear, worry or concern relating to the possibility that cancer will come back or progress,”¹(p. 3266) is a key concern reported by people living with cancer and their caregivers. Previous studies suggest caregivers experience similar or higher levels of FCR compared to people living with and beyond cancer.^{2,3} Comparatively little research has been conducted to examine caregiver FCR.⁴ Therefore, we aimed to conduct a systematic review and meta-analysis of caregiver FCR to:

1. Compare caregiver and survivor FCR levels
2. Quantify the proportion of caregivers scoring above clinical cut-offs
3. Examine the relationship between caregiver FCR and depression, and anxiety
4. Evaluate the psychometric properties of caregiver FCR measures

Method and Results:

- PRE-REGISTRATION**
PROSPERO ID:
CRD42020201906
- SEARCHES**
November 2022
Databases: PsycINFO, PubMed, CINAHL, Embase
- STUDY QUALITY:**
NIH quality assessment tool⁵
Instruments: COSMIN⁶
- INCLUDED STUDIES:**
Of 4297 identified articles, 45 met the full inclusion and exclusion criteria

1A. DO CAREGIVERS HAVE AS MUCH FCR AS SURVIVORS?

- No significant difference:
($k = 24$; $g = 0.099$; 95% CI -0.045 to 0.242, $p = .178$)
- Considerable heterogeneity:
 $Q = 204.122$, $p < .0001$, $I^2 = 85.793$; 95% CI -0.656 to 0.854

1B. WHAT IS THE RELATIONSHIP BETWEEN CAREGIVER AND SURVIVOR FCR?

- Moderate correlation⁷
($k = 17$; $r = .338$, $p < .001$; 95% CI .283 to .392)
- Considerable heterogeneity
($Q = 71.376$, $p < .001$, $I^2 = 74.781$)

2. WHAT PROPORTION OF CAREGIVERS REPORT CLINICALLY SIGNIFICANT LEVELS OF FCR?

Almost half (48%) of caregivers reported levels deemed clinically significant in survivor populations ($k = 13$)

- **Survivor cut-offs:**
 - Fear of Cancer Recurrence Inventory (≥ 13)^{8,9}
 - Fear of Progression Questionnaire (Parent and Partner versions) (≥ 34)¹⁰

3. WHAT IS THE RELATIONSHIP BETWEEN CAREGIVER FCR AND ANXIETY AND DEPRESSION?

- Anxiety:**
- Large correlation⁷
($k = 12$; $r = .561$, $p < .001$, 95% CI 0.453 to 0.653)
 - Considerable heterogeneity: $Q = 90.128$, $p < .001$, $I^2 = 89.905$
- Depression:**
- Large correlation⁷
($k = 11$; $r = .533$, $p < .001$, 95% CI 0.447 to 0.609)
 - Considerable heterogeneity: $Q = 36.455$, $p < .001$, $I^2 = 75.312$

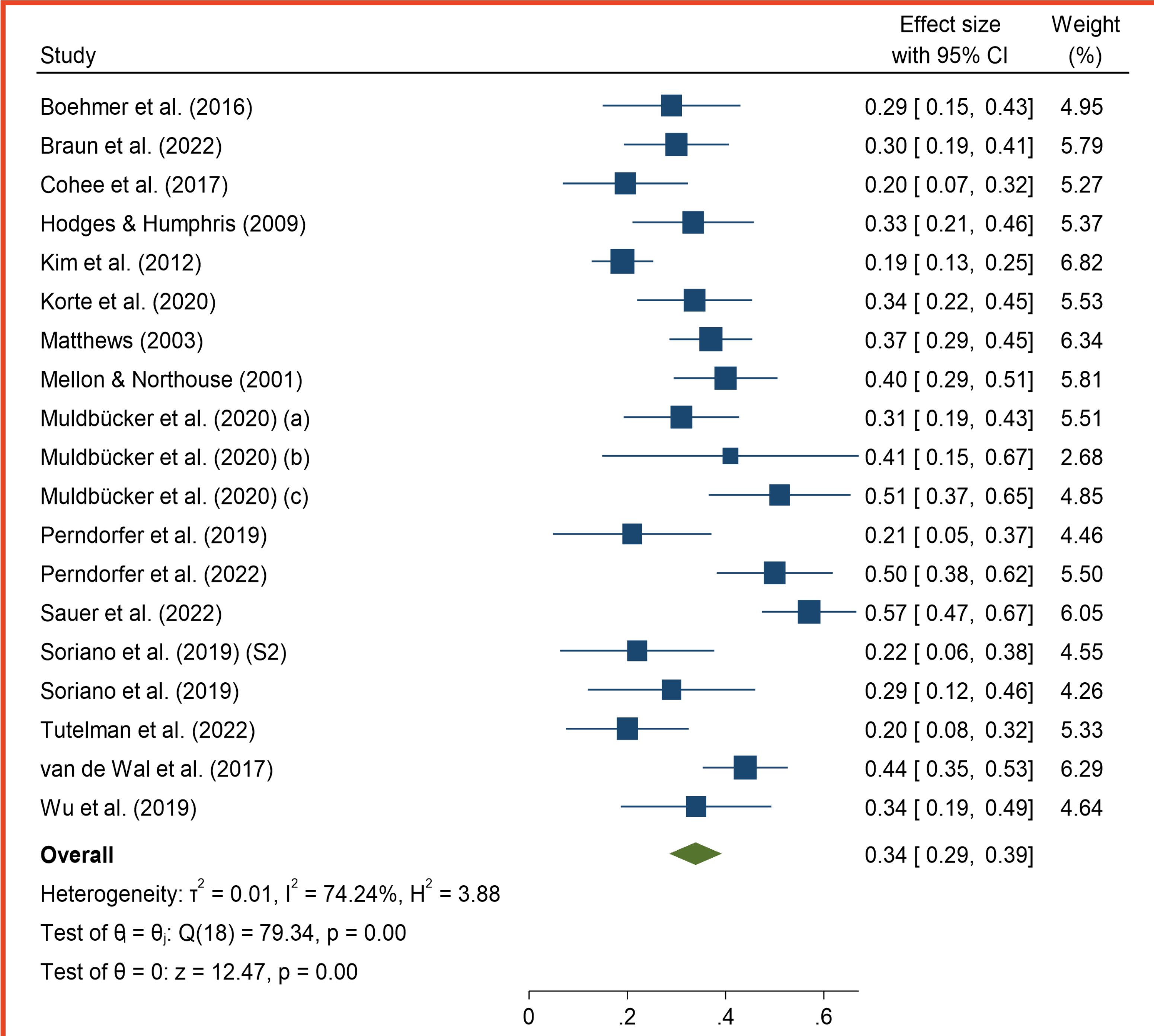


Figure 1: (A) Forest plot of effect sizes for standard difference in means for fear of cancer recurrence (FCR) levels in survivor and caregiver populations. Note: weights are from random effects analysis. * Letter indicative of sub-group, *S1 and S2 indicates study 1 and study 2.

4. WHAT ARE THE PSYCHOMETRIC PROPERTIES OF INSTRUMENTS USED TO MEASURE CAREGIVER FCR?

- 12 different multi-item instruments used to measure caregiver FCR
- Assessment using the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) found:
 - 1 measure met >50% of criteria (FoP-Q-SF/PR = 50%)
 - Reliance on measures developed for cancer survivors with adaptations (e.g., using “their” before cancer, removing irrelevant items)
 - Substantial item generation components missing

Conclusions:

- Caregiver FCR levels are as high as survivor FCR levels.
- Around 48% of caregivers report clinically significant levels of FCR.
- Large associations were found between caregiver FCR and depression and caregiver FCR and anxiety.
- Further research needed to examine caregiver experiences of FCR, facilitating intervention development to address caregiver needs.

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View the publication:

