CANCER SUPPORT COMMUNITY
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Talking About Cachexia: Foundational Research for a Patient-Centric Cachexia Lexicon for Patients, Caregivers, and Healthcare Professionals

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BACKGROUND

- Cancer cachexia is a multifactorial syndrome that is characterized by anorexia, weight loss, muscle loss, asthenia, and anemia.
- Studies focused on cancer cachexia span from physical to psychosocial aspects of the disease.
- The definitions and measures associated with cancer cachexia are not well aligned in the literature.
- This research represents the results of the first of five phases associated with this project.

OVERALL PROJECT AIMS

- To investigate and analyze articles related to cancer cachexia published from January 1, 2019, to February 14, 2022.
- Materials educating patients/survivors, caregivers, advocates, and clinicians on a plain language cachexia lexicon. To disseminate completed materials to stakeholders as best practices.

PHASE 1 OBJECTIVES/OUTCOMES

- Establish Advisory Board and Coalition of industry KOLs.
- Complete a scoping review of the literature.
- Complete a survey landscape analysis of the Coalition.
- Engage in preliminary discussions with key stakeholders about gaps in knowledge and communication to be addressed.

METHODS

- This scoping review considered all studies that addressed cancer cachexia. A three-step search strategy was undertaken:

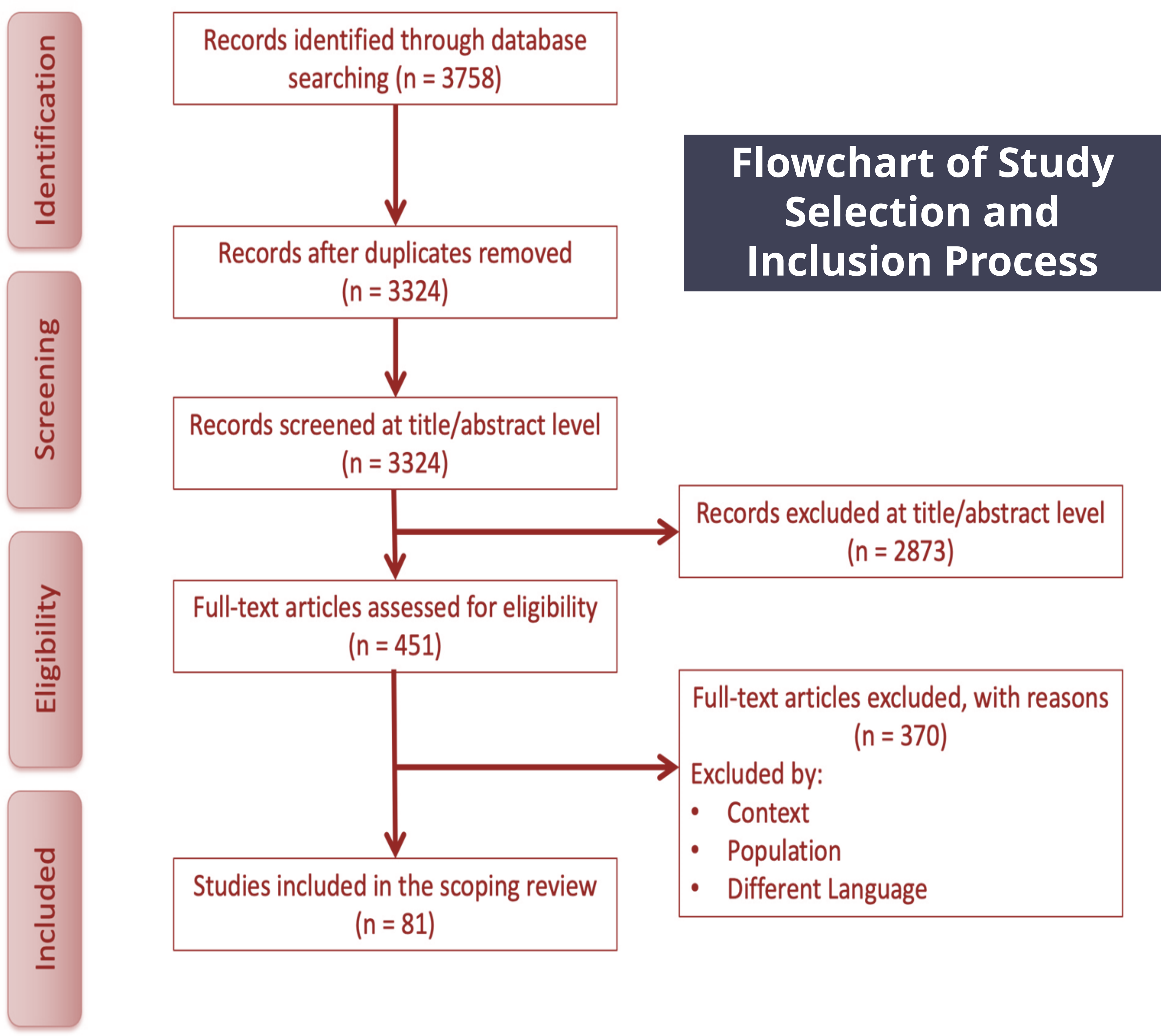
1) An initial limited search of PubMed
2) An extensive search using all identified keywords; and
3) A hand search of the reference lists of included articles.

- This review was limited to studies published in English from January 1, 2019, to February 14, 2022. Reviewers extracted data independently; disagreements that arose between the reviewers were resolved via discussion, or with a third reviewer.

LITERATURE REVIEW RESULTS

A total of 3324 articles were screened
451 full text publications were reviewed
136 relevant articles were identified
81 studies and 55 reviews were ultimately included

- Most studies focused on physical aspects of cachexia
- Multiple review articles discussed treatment algorithms and consideration for treatment of patients with cancer cachexia
- Relatively few articles focused specifically on the psychosocial aspects of cancer cachexia (7.4% of relevant articles)
- Articles came from more than 17 countries and were representative of quantitative, qualitative, and review designs



Flowchart of Study Selection and Inclusion Process

Identification

Records identified through database searching (n = 3758)

Records after duplicates removed (n = 3324)

Screening

Records screened at title/abstract level (n = 3324)

Records excluded at title/abstract level (n = 2873)

Eligibility

Full-text articles assessed for eligibility (n = 451)

Full-text articles excluded, with reasons (n = 370)
Excluded by:
- Context
- Population
- Different Language

Included

Studies included in the scoping review (n = 81)

ACKNOWLEDGMENTS

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QUALITATIVE RESULTS

Results were collected from calls with Advisory and Coalition Board calls. These calls were open discussions with KOLs with the purpose of identifying shared definitions as well as gaps and misnomers within the currently used cachexia lexicons.

- Balance of realistic expectations – avoid the overly negative without giving false hope
- Focus on action – what can people with cachexia do?
- Differences in manifestation – dependent on sociocultural, physical, genetic, and situational
- Characterization – condition vs. syndrome vs. other categorical terms

CONCLUSIONS AND FINDINGS

- The most evaluated aspect of cancer cachexia was the physical impact on patients
    - Only 6 articles (7.41%) discussed the psychosocial aspects
    - Only 1 article described bot psychosocial and physical components of cancer cachexia
    - To fully demonstrate patients' needs for psychosocial support regarding cancer cachexia, all 6 articles would need to be synthesized.
    - Only 2 articles (2.47%) had a focus on caregivers
- Inclusion of all components will be beneficial for developing a lexicon to standardize the way we talk about cachexia
    - Avoiding inadvertent patient confusion and distress
    - Providing clear information
    - Ensuring appropriate awareness among patients and caregivers

IMPLICATIONS FOR RESEARCH/FUTURE DIRECTIONS

- Future primary research should focus on the psychosocial aspects of cancer cachexia for both patients and their caregivers, and more studies should focus on the impact of cancer cachexia on caregivers and their quality of life.
- Development of a prototype for a plain language cachexia lexicon to be tested with patients/survivors, caregivers, patient advocates, and clinicians. Later disseminated to stakeholders as best practices.

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