

# Information needs among family members affected by childhood cancer: A systematic review

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## Background

### Childhood cancer

- One of the leading causes of children death [1]
- 5-year survival rate (CH): 88% [2]
- High risk of late effects [3]
- Entire families are affected [4]

### Information needs of family members

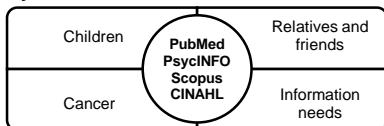
- Information needs are:
  - Context-dependent [5]
  - Subjective [5]
- Fulfillment is related to better coping [6]

## Aim

To summarize the current knowledge on the information needs around childhood cancer among relatives and close friends of childhood cancer patients and survivors.

## Methods

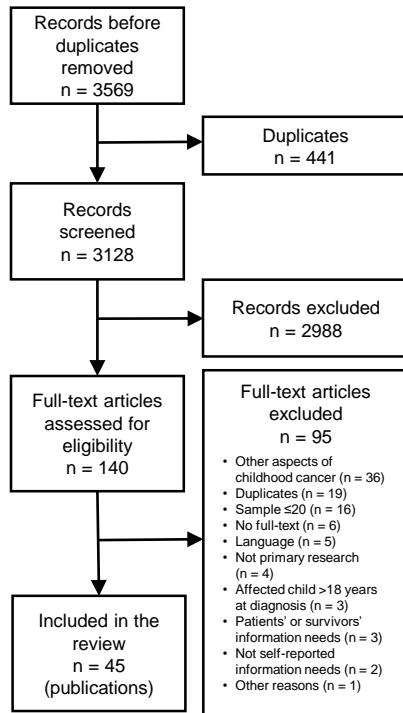
### Systematic database search



### Analysis

- Descriptive statistics
- Thematic analysis (ongoing)

## PRISMA Flow Diagram



## Preliminary Results

| Characteristics                       | N  | %    |
|---------------------------------------|----|------|
| <b>Publication year</b>               |    |      |
| 1989-1999                             | 5  | 11.1 |
| 2000-2009                             | 15 | 33.3 |
| 2010-2019                             | 25 | 56.6 |
| <b>Country</b>                        |    |      |
| USA                                   | 16 | 36.6 |
| Australia                             | 6  | 13.3 |
| UK                                    | 5  | 11.1 |
| Other                                 | 18 | 40.0 |
| <b>Methodology</b>                    |    |      |
| Quantitative                          | 35 | 77.7 |
| <i>Cross-sectional</i>                | 33 | 73.3 |
| <i>Longitudinal</i>                   | 2  | 4.4  |
| Mixed methods                         | 7  | 15.5 |
| <i>Cross-sectional</i>                | 6  | 13.3 |
| <i>Longitudinal</i>                   | 1  | 2.2  |
| Qualitative                           | 3  | 6.6  |
| <i>Cross-sectional</i>                | 1  | 2.2  |
| <i>Longitudinal</i>                   | 2  | 4.4  |
| <b>Relationship to affected child</b> |    |      |
| Parents / primary caregivers          | 37 | 82.2 |
| Siblings                              | 4  | 8.9  |
| Grandparents                          | 1  | 2.2  |
| Multiple categories of relatives      | 3  | 6.7  |
| <b>Sample size (relatives)</b>        |    |      |
| 20-99                                 | 24 | 53.3 |
| 100-199                               | 8  | 17.8 |
| 200-299                               | 3  | 6.7  |
| 300-399                               | 3  | 6.7  |
| ≥400                                  | 2  | 4.4  |
| No / contradictory information        | 5  | 11.1 |

Note: Totals may not add up to 100% due to rounding.

## Conclusions

- First systematic review on relatives' information needs in the context of childhood cancer
- High prevalence of English-speaking countries
- Lack of qualitative and longitudinal research
- Research is focused on parents and other primary caregivers
- No research on close friends

## References

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