

# The Role of Religion and Spirituality in Parent Decision Making for Seriously Ill Children



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## BACKGROUND

Approximately 85% of African Americans and 58% of Caucasians say religion is very important in their lives.<sup>1</sup> More specifically, significant literature cites parents' use of religious coping in pediatric decision making. While parents are understood to be the appropriate surrogate when their child becomes ill,<sup>2</sup> what is less clear is how parents utilize religion and spirituality during the decision making process for their ill child. An exploration of existing research that examines religion, spirituality and parent decision making will inform the development of decision support interventions that promote parent engagement in complex pediatric decision making.

## PURPOSE

To systematically review the literature describing the role of religion and spirituality in decision making for parents of hospitalized children who are seriously ill.

## METHODS

In consultation with a health librarian, the following databases were searched in January 2017 using medical subject headings (MeSH) and non-MeSH search terms (*religion, spirituality, decision making, parents/mother/father/surrogate*): PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL plus), Embase, Scopus, and PsychInfo.

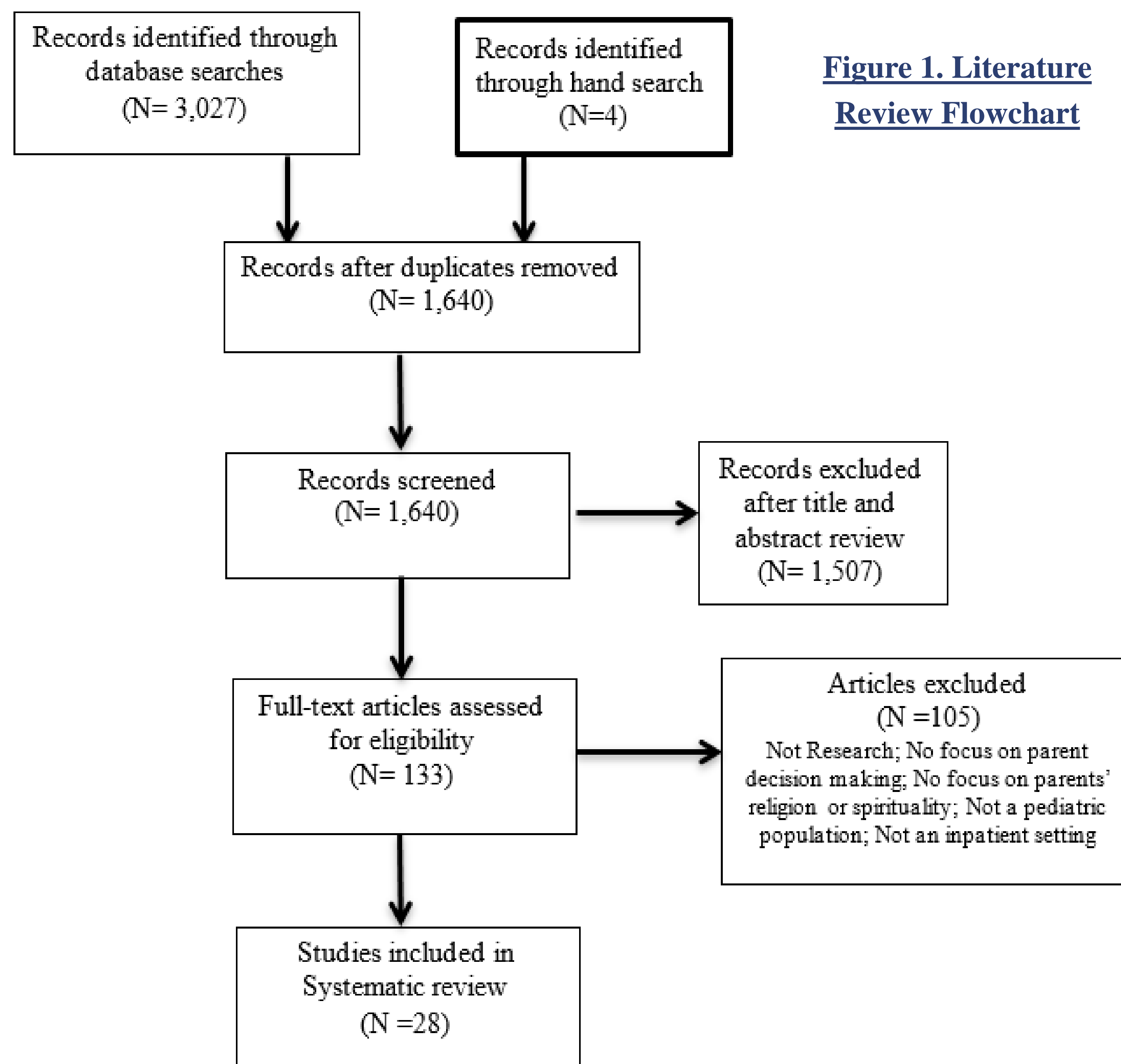
Articles were included if they satisfied the following eligibility criteria: 1) Primary, peer-reviewed research articles; 2) Addressed the relationship between parents' spirituality or religion and their medical decision making for children; 3) Discussed decision making in the acute care setting. Studies were excluded if the research focus was on 1) Public health topics (i.e. decisions related to health screening and vaccinations); 2) Decisions of a less critical nature (i.e. circumcision and breastfeeding); 3) Decision making from the health provider's perspective; 4) Decisions about the use of complimentary or alternative medicine; or 5) Decisions related to participation of a child in research.

## RESULTS

The literature search yielded 3,027 potentially relevant articles; 4 articles were identified through hand search. After duplicates were removed, 1,636 relevant articles remained. Of these articles, 28 met inclusion criteria. Seventeen studies were qualitative, nine studies were quantitative, and two utilized mixed methods. The majority of studies (57%) were conducted in the United States. Decisions discussed included: end-of-life (EOL), palliative care, delivery room resuscitation or treatment decisions for very premature infants, cancer treatment, or BMT.

## REFERENCES

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## SUMMARY OF THEMES

### Finding meaning in the decision making process

Spirituality and/or religion were useful for parents seeking to find meaning in the decision making process. Parents sought meaning through connectedness to God or others during the illness when decisions were made. Spirituality was also a source of motivation for parents to offer meaning to other parents making decisions for their ill child.

### Spirituality and religion as a guiding force during decision making

Several articles discussed parents' reliance upon their spirituality or religion for guidance when making decisions for their critically ill child. In some of these studies, parents reported prioritizing religious beliefs over medical information from the health care team. In other studies, religion/spirituality was the primary reason for refusing or advocating for life sustaining treatments. Religious beliefs also guided parents in their moral responsibilities/beliefs as parents.

### Use of spirituality and religion as support in coping with the critical illness or death outcome of a child

Many articles discussed parents' use of spirituality or religion as a source of support in coping with the critical illness or death of a child. Parents used religion/spirituality to achieve a close relationship with God or others, fill a void created by grief, and facilitate close relationships among family members.

## CONCLUSION

This review highlights some of the ways in which parents may utilize religion and spirituality when faced with decision making for their seriously ill child. Several limitations noted in these studies, including small sample sizes in quantitative studies, clinically and geographically homogenous samples, and the retrospective nature of many studies, could be addressed in future research. These findings could be helpful in guiding the development of decision support interventions for parents holding different religious/spiritual views and with diverse spiritual care needs.