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The R|S Atlas: Accelerating Epidemiological Research on the Influence of Religion and Spirituality on Human Health

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COMPETING INTERESTS

The authors declare no conflicts of interest.

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ABSTRACT

Objectives: Many studies have documented significant associations between religion and spirituality (R/S) and health, but relatively few prospective analyses exist that can support causal inferences. To date, there has been no systematic analysis of R/S survey items collected in U.S. cohort studies. We conducted a systematic content analysis of all surveys ever fielded in 20 diverse U.S. cohort studies funded by the National Institutes of Health (NIH) to identify all R/S-related items collected from each cohort's baseline survey through 2014. An R|S Ontology was developed to categorize all R/S survey items identified into key conceptual categories. A systematic literature review was completed for each R/S item to identify any cohort publications involving these items through 2018.

Setting: The data were collected from 20 diverse NIH-funded cohort studies.

Participants & Interventions: n/a

Measures: The content analysis was of all R/S survey items collected from 20 NIH-funded cohorts, from baseline through 2014.

Results: Our content analysis identified 319 R/S survey items, reflecting 213 unique R/S constructs and 50 R|S Ontology categories. 193 of the 319 extant R/S survey items had been analyzed in at least one published paper. Using these data, we created the R|S Atlas (https://atlas.mgh.harvard.edu/), a publicly available, online relational database that allows investigators to identify R/S survey items that have been collected by U.S. cohorts, and to further refine searches by other key data available in cohorts that may be necessary for a given study (e.g., race/ethnicity, availability of DNA or geocoded data).

Conclusions: R|S Atlas not only allows researchers to identify available sources of R/S data in cohort studies, but will assist in identifying novel research questions that have yet to be explored within the context of U.S. cohort studies.

KEYWORDS

Cohort Study, Epidemiology, Religion, Spirituality, Ontology, Public Health, Relational Database, Health Disparities

ARTICLE SUMMARY

- We conducted the first systematic analysis of religion and spirituality (R/S) survey items ever collected by a group of 20 NIH-funded cohort studies in the U.S. Results from this systematic content analysis are searchable in R|S Atlas - a publicly available, online database (https://atlas.mgh.harvard.edu).
- Cohorts included in R|S Atlas include diverse participant populations and contain a wide range of measures on clinical and health outcomes.
- R|S Atlas allows researchers to search for R/S items that are available in existing U.S. cohort studies and that could be used to conduct immediate prospective analyses.
- R|S Atlas will also assist in identifying novel R/S research questions that have yet to be explored within the context of U.S. cohort studies.

INTRODUCTION

Over the past 20 years, religion and spirituality (R/S) have been increasingly recognized as important resources for resilience that have both protective and deleterious effects on human health.[1,2] Measures of R/S have been prospectively associated with several mental health outcomes, including reduced risk of depression,[3,4] anxiety or emotional distress,[5] and risk of suicidal attempts.[6,7] Prospective analyses of chronic disease risk have associated various measures of R/S with lower blood pressure and reduced risk of hypertension,[8,9] cardiovascular events,[10] obesity,[11] mortality,[12-14] and higher self-rated health.[15-18] Multiple studies, including several randomized controlled trials, have shown that spiritual practices such as yoga and meditation increase expression of genes associated with enhanced mitochondrial function and insulin secretion, and reduce expression of genes linked to inflammation and the stress response.[19-22] Additional research is needed, however, to identify the mechanisms or pathways through which other dimensions of R/S may work to influence risk of disease.

Despite promising advancements, R/S research has been hampered by the relatively few high-quality prospective studies conducted with adequate sample sizes, the limited dimensions of R/S assessed, and the predominance of white, Christian study populations. A systematic review of studies published from 2000-2010 assessing R/S influences on depression, for example, found that only 45 of 339 extant studies were prospective, and several of these were rated as poor quality despite their prospective study design.[2] The relatively small number of prospective studies on R/S and health is due, in part, to a lack of R/S survey items routinely collected by U.S. cohort studies. Currently, very few cohort studies collect more than a few R/S items, and, when they do, a scientific rationale for item selection is often lacking.[23] Many R/S survey items collected by cohorts have also never been analyzed due to

lack of National Institutes of Health (NIH) funding in this area.[23] In 2019, R/S-related research received approximately 0.2% of all NIH research dollars spent.[a]

No study to date has systematically assessed which R/S survey items have been collected by U.S. cohort studies and are currently available to support prospective analyses of R/S influences on health. To address this gap in the literature and to facilitate prospective analyses investigating the influence of R/S on health, we: (1) conducted a content analysis of all surveys ever fielded by 20 NIH-funded U.S. cohort studies, in order to identify all R/S-related survey items fielded from each cohort's inception through 2014; (2) developed an R|S Ontology that maps all of the R/S items identified in our content analysis into a hierarchy of theologically meaningful conceptual categories; (3) conducted a systematic review to identify which of these R/S items have been analyzed in a published study; and (4) created R|S Atlas, a platform that organizes all of this information into an open-access, searchable, online research tool to facilitate prospective R/S analyses and advance understanding of the influence of R/S on the human health.

[a] Funding statistics were gathered using NIH RePORTER version 7.41.0 (https://projectreporter.nih.gov/reporter.cfm). Data are current as of April 18, 2020. Search terms used for R/S-related projects were:

Religion OR religious OR religiosity OR spiritual OR spirituality OR Buddhism OR Confucian OR Hindu OR Shinto OR Sikh OR Islam OR Muslim OR Judaism OR Taoism OR Daoism OR Bible OR church OR mosque OR synagogue OR ecumenical OR theology OR theological OR rabbi OR priest OR minister OR swami OR gurdwaras OR ashram OR pray OR prayer OR meditation OR worship OR God OR Allah

These terms were used to search all project abstracts and titles for fiscal year 2019. 171 R/S-related projects were awarded a total of $73,001,180 in 2019, compared with a total of $36,206,577,792 in 2019 NIH funding across 66,918 projects.

Note: the terms "Christian," "Jewish," "Jain," and "temple" were omitted because they retrieved projects unrelated to R/S with these terms in the names of hospitals, universities, and investigators listed.

METHODS

Selection of Cohorts

We generated a list of 35 NIH-funded cohort studies, prioritizing cohorts for inclusion in this list that represented diverse racial/ethnic communities (in order to support disparities-focused research), as well cohorts representing diverse clinical outcomes and large, national samples. Outreach to principal investigators (PIs) of these 35 cohorts was conducted until 20 PIs agreed to have their cohorts included in this analysis.

Extraction of R/S Items from Cohorts' Survey Instruments

All primary survey instruments, and as many ancillary instruments as possible, were collected from these 20 cohorts by use of study websites and/or assistance from cohort investigators. Surveys encompassed each cohort's first round of data collection through to their latest survey (through 2014), regardless of survey administration method (i.e., online, mail, or in-person) or population (e.g., the full cohort or a sub-population, such as an ancillary study).

Research Assistants reviewed each survey instrument and recorded all survey items related to R/S, specifically looking for questions or response categories containing words or cognates of spirituality, religion, faith, God, higher power, divine, church, worship, Sabbath, prayer, congregation, clergy, priest, or meditation. Survey items were considered R/S in nature if the question, response category, or section header contained R/S-related content. The inclusion of each item, as well as the recorded contextual information related to each R/S survey item (e.g., source instrument, study population in which the question was fielded, full question, and response categories) and key cohort characteristics (e.g., year of inception; sample size; composition of cohort by race/ethnicity, sex, age; and whether the cohort was

geocoded and/or collected DNA samples) were checked by a second reviewer and any differences reconciled.

The basic unit of information extracted from cohort surveys to include as searchable items in R|S Atlas were individual R/S items from the surveys, regardless of format in which they were collected or asked. Depending on the cohort and the survey, an item might be a standalone measure, a sub-item from a larger scale, or a response category from a survey question (e.g., an R/S-related response category from a question asking the respondent to "mark all that apply"). Each R/S-related response category in a "mark all that apply" question was considered a different item to add to R|S Atlas. The same question asked to the same cohort population in multiple years was classified as a single item (users can see "Years Asked" information for each item within R|S Atlas to identify repeated items for each cohort). However, the same question asked by different cohorts, or even the same question asked to different groupings within the same cohort (e.g., a cohort's full exam vs. that cohort's ancillary study sub-population) were classified as separate individual items for the purpose of this content analysis. Likewise, questions similar in meaning but using different wording or response categories were also counted as multiple individual items. Classifying and counting survey items in this way was necessary in order to ensure that R|S Atlas conveys the full scope of R/S information collected and available in each cohort at the most granular level possible.

To allow researchers to understand the number of unique R/S constructs that each cohort has collected, however, we also collapsed groups of individual R/S survey items that are functionally identical or repeated (by the same cohort, different cohorts, or different cohort subgroups) into larger units of unique, non-overlapping constructs ("unique R/S constructs"). Examples of these unique R/S constructs include "How often do you attend religious services or organized religious activities?" (which combines individual R/S survey items such as "How often do you go to religious meetings or services?" or "How often do you attend church or other religious meetings?") and "What is your religious affiliation?" (which combines individual R/S

survey items such as “What religion would you identify yourself with?” or “What is your religious affiliation?”). Grouping items by unique R/S constructs provides a heuristic way to count units of information contained in R|S Atlas that are unique, non-overlapping R/S constructs. Additional work will need to be done to analytically harmonize the items within these unique constructs across cohorts prior to being used in analyses.

Development of the R|S Ontology

Based on our content analysis, and drawing from published literature and input from R/S and informatics experts, we developed an R|S Ontology that organizes the diverse R/S information we identified into theologically meaningful concepts and categories. As new R/S items were collected throughout our content analysis, we iteratively refined our R|S Ontology by mapping each R/S item onto our initial high-level concepts, and then adding, removing, or merging concepts in the R|S Ontology as needed so that all items would be captured by a category. We also created sub-categories (e.g., dividing “Coping” into “Religious Coping” and “Spiritual Coping”), where appropriate, to further refine the R|S Ontology. Throughout this process, input was provided by R/S and informatics experts and further adjustments made until all identified R/S items across all 20 cohorts were mapped onto theologically coherent categories and sub-categories in the R|S Ontology.

Identification of R|S Atlas Items Used in Published Analyses

Using PubMed, we then performed a systematic literature review (through 2018) for each R/S item collected in each cohort (combining keywords from the item with the name of the cohort into a unique search string for each review) to produce an exhaustive list of publications (if any) resulting from the collection of each R/S survey item in each of the 20 cohorts.

Development of the R|S Atlas Query Tool

Once all R/S items were identified from cohort surveys and classified according to our R|S Ontology, we incorporated them (along with the cohort data we had collected) into an online relational database called "R|S Atlas." To make this a functional and broadly useful tool, we worked with informatics and web design experts to develop R|S Atlas' foundational structure, search algorithms, and user interface.

Patient and Public Involvement

No patients or members of the public were involved in the design or recruitment of our study, nor in the dissemination of results.

Research Ethics Approval

As our research activities with the cohort studies were limited to content analysis of cohort survey questionnaires, this work is not considered human subjects research. Therefore, research ethics approval was not pursued or obtained.

RESULTS

Content Analysis

In total, we analyzed more than 200 survey instruments, representing thousands of pages and up to 67 years (1948-2014) of data collection. We identified a total of 319 R/S survey items across all cohorts, each of which is searchable in R|S Atlas as a discrete piece of

information. The cohort collecting the most individual R/S survey items was the Adventist Health Study-2 (n=147), followed by the Hispanic Community Health Study/Study of Latinos (n=38). Aside from the religion-focused Adventist Health Study-2, only 172 R/S survey items have been collected across all of the remaining 19 cohorts. 13 cohorts collected 5 or more R/S survey items, and only 7 cohorts collected 10 or more items. After reviewing all R/S survey items for conceptual overlap, we arrived at a list of 213 unique R/S constructs collected across all cohorts. See **Table 1** for a complete list of participating cohort studies, their year of inception, and the number of individual R/S survey items and unique R/S constructs collected per cohort.

We identified 16 validated scales through our content analysis, represented (either in full or via selected sub-items used on surveys) by 193 R/S survey items. The scales most commonly represented by items in the R|S Atlas were the FACIT-Sp (n=41) and RCOPE (n=31). See **Table 2** for the validated scales represented in R|S Atlas (including citations and the number of R/S survey items and unique R/S constructs that relate to each scale).

R|S Ontology

The R|S Ontology comprises 50 concepts distributed across 12 high-level categories. Ontology categories most often captured by extant cohort R/S survey items were Religious Coping (n=38), Religious Meetings or Services (n=22), and Quality of Relationships among Religious Community Members (n=22). **Table 3** presents our final R|S Ontology and the number of R/S survey items and unique R/S constructs included in the R|S Atlas that map onto each Ontology category. As this table shows, many concepts have only rarely been asked in most cohorts.

R|S Atlas Items Analyzed in Previously Published Analyses

We identified a total of 104 publications that analyzed 193 R/S survey items contained in R|S Atlas. The greatest number of publications were related to the categories of Religious Service Attendance (N=39) and Religious and Spiritual Coping (N=23). The Adventist Health Study 2 (AHS-2) had the most R/S publications (N=18, assessing a total of 101 individual R/S survey items), while the remaining 19 cohorts published a total of 86 studies examining R/S survey items included in the Atlas.

R|S Atlas Query Tool

We integrated our R|S Ontology, cohort characteristics, and R/S items identified through our content analysis into an open-access data resource, R|S Atlas (https://atlas.mgh.harvard.edu). The cohort is the unit of analysis represented in R|S Atlas. The R|S Atlas Query Tool search options include searching by keyword, searching via a Boolean drag-and-drop feature, and filtering results by keyword. Once searches are complete, users may also sort search results according to different criteria. The search functions provided by R|S Atlas are designed to help researchers identify which R/S items are available in which cohorts, so that they may contact those cohorts to request access to individual-level data.

The R|S Ontology, which forms the backbone of the R|S Atlas, provides a user-friendly way for investigators new to R/S research to find data, as they need not know the specific R/S terms that apply to their research; rather, they may simply select categories represented in the Ontology to search for survey items contained within that category. For example, selecting the Ontology concept of “Private Religious Practices” would retrieve many different types of survey items; e.g., “How often do you pray” (BWHS); “I pray or meditate [Not at all, A little, Medium, a lot]” (NHS II); “How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?” (HCHS/SOL).

R|S Atlas also allows users to simultaneously cross-reference R/S survey items with demographic characteristics of cohorts (e.g., religious coping survey items administered in African American or female populations), and/or query a number of demographic (e.g., age, sex, or racial/ethnic composition) and other key cohort characteristics (e.g., availability of geocoded data or DNA samples). Lastly, the R|S Atlas Query Tool retrieves information from our literature review, which allows investigators to identify new, unstudied research questions for each Atlas item that could be immediately pursued.

The R|S Atlas website includes descriptions and links for each of the participating cohorts (via the "Cohorts" page) to facilitate investigators directly contacting individual cohorts that have the data they need to support their proposed analysis, and includes a "Resources" page that provides additional information and links on established scales represented in the Atlas, citations and links for cohorts' publications that use R/S survey items in the Atlas, and links to some additional web resources related to R/S research.

DISCUSSION

Advancing knowledge regarding the role of R/S in health will likely require a two-pronged approach: (1) maximizing the usefulness of existing data to assess the influence of R/S on diverse health outcomes; and (2) persuading individual cohorts to collect additional R/S survey items to support prospective studies on a wider array of R/S variables. Our work, culminating in the development of R|S Atlas, helps address each of these challenges.

First, the searchable nature of R|S Atlas will help researchers identify existing R/S survey items that could be used immediately to conduct prospective studies investigating the influence of R/S on various clinical endpoints. R|S Atlas allows researchers to identify novel analyses, focusing on unstudied R/S items, clinical outcomes, or cohort populations. R|S Atlas will also aid users in identifying R/S items available across several cohorts, which will facilitate comparative, pooled, or meta-analyses. For example, the R|S Atlas shows that NHS II,

HCHS/SOL, MESA, and WHI are among the cohorts having collected a survey item on religious service attendance; investigators could therefore propose to conduct robust, comparative analyses on religious service attendance and health across a large and diverse set of white, Black, Hispanic/Latino, and Asian cohort participants.

Second, the relatively low number of different dimensions of R/S measured by this sample of 20 cohorts (**Table 1**) illustrates the need to expand the collection of R/S data in cohort studies in order to understand the complex ways in which R/S affect human health. R|S Atlas demonstrates that there are several important dimensions of R/S that are under-collected in U.S. cohorts (**Tables 2** & **3**). Survey items addressing more functional aspects of R/S, such as using positive religious coping, and even negative R/S experiences such as spiritual struggles and negative religious coping,[40-45] may be especially significant R/S influences affecting the etiology of disease that remain understudied.

This study has several limitations that should be noted. First, our cohort sample was not random. While the results may not be generalizable to all U.S. cohorts, our cohorts represent a variety of clinical conditions, racial/ethnic communities, and regions of the U.S. Second, while we are confident that our content analysis included all surveys of each cohorts' main study populations, cohorts varied in their ability to identify and provide survey instruments for past ancillary studies. Thus, some R/S survey items collected by smaller ancillary studies may not be included. Third, while we made efforts to include cohorts that represented diverse racial/ethnic communities, these 20 cohorts do not include all sub-populations in the U.S. (e.g., other American Indian sub-populations, Pacific Islanders). Fourth, the additional information we provide for each cohort (e.g., whether the cohort has geocoded data) is not exhaustive. Future efforts could expand the information provided on each cohort to allow more comprehensive searches. Lastly, the information presented in R|S Atlas is only representative of cohort data collection efforts through 2014, although we have begun to add more current data.

Despite these limitations, our work represents the first systematic assessment of R/S survey items currently available within NIH-funded cohort studies, and addresses several

barriers to better understanding the impact of R/S on health. R|S Atlas enables investigators to easily identify novel R/S analyses that could be conducted across multiple cohort studies. The R|S Ontology, constituting the conceptual structure of R|S Atlas, also facilitates harmonizing R/S survey items across cohorts, offering a framework for tracking and comparing items by conceptual category across additional cohort studies. Our hope is that R|S Atlas will facilitate additional high-quality, prospective studies of R/S and health in cohort study populations.

AUTHORS' CONTRIBUTIONS

ABS, BS, LM, and AES led the systematic content analysis. ABS, MAA, BS, LM, and AES developed the R|S Atlas database, with conceptual input from KIP and LU, and technical input from PT and ATM, on development and refinement of the ontology. BVK contributed to further refinements of the database and ontology categories after initial drafts were completed. MM built the R|S Atlas website and implemented all backend work on the website. ABS, MAA, MM, and AES contributed to the design and functionality of the website. ABS, MAA, BS, OI, BVK, and AES contributed to the writing and developing the manuscript.

DATA SHARING

Aggregate, cohort-level data are available to search and download via the R|S Atlas website. Individual-level data are available for analysis upon contacting the relevant cohort(s). Researchers will need to obtain ancillary study approval, execute appropriate data use agreements, and receive IRB approval (or equivalent) before individual-level data may be accessed from cohorts.

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Table 1. 20 Cohort Studies Participating in R|S Atlas (including the year each cohort began, and the number of R/S survey items and unique constructs collected), through 2014

Cohort Study Name	Year Initiated	Individual R/S Survey Items (N = 319)	Unique R/S Constructs (N = 213)
Adventist Health Study-2 (AHS-2)	2002	147	128
Black Women's Health Study (BWHS)	1995	8	7
Cancer Prevention Study II (CPS II)	1982	3	2
California Teachers Study (CTS)	1995	5	5
Framingham Heart Study (FHS)	1948	10	9
Hispanic Community Health Study/Study of Latinos (HCHS/SOL)	2008	38	35
Health Professionals Follow-Up Study (HPFS)	1986	7	4
Jackson Heart Study (JHS)	2000	13	12
Mediators of Atherosclerosis in South Asians Living in America (MASALA)	2010	3	3
Multiethnic Cohort Study of Diet and Cancer (MEC)	1993	1	1
Multi-Ethnic Study of Atherosclerosis (MESA)	2000	13	11
Nurses' Health Study (NHS I)	1976	2	2
Nurses' Health Study II (NHS II)	1989	16	14
Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO)	1993	1	1
Project Viva (Viva)	1999	3	3
Southern Community Cohort Study (SCCS)	2002	7	7
Strong Heart Study (SHS)	1989	7	7
The Sister Study	2004	7	5
Women's Health Initiative (WHI)	1993	25	15
Women's Health Study (WHS)	1993	3	2

Table 2. 16 Validated scales represented in R|S Atlas (and the number of R/S survey items and unique constructs that fall under each scale), through 2014

Validated Scale	Individual R/S Survey Items (N=319)	Unique R/S Constructs (N = 213)
Berkman-Syme Social Network Index[24]	16	5
Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS)[25,26]	24	19
Congregational Sense of Community[27]	10	10
COPE[28]	2	2
Coping Strategies Inventory Short-Form (CSI-SF)[29]	1	1
Daily Spiritual Experiences (DSES)[30]	15	11
Duke University Religion Index (DUREL)[31]	8	6
Functional Assessment of Chronic Illness Therapy - Spiritual Well-being Scale (FACIT-Sp)[32]	41	25
Gratitude Questionnaire (GQ-6)[33]	6	6
Health Care Preferences Questionnaire[34]	2	2
JHS Discrimination (JHSDIS) Instrument[35]	2	1
Multiphasic Assessment of Cultural Constructs - Short Form (MACC-SF)[36]	1	1
RCOPE[37]	31	29
Sabbath and Endtime Scale	20	13
Spiritual Meaning Scale[38]	5	5
Structure of Prayer[39]	9	9

Table 3. Structure of the R|S Ontology (including the number of R/S survey items and unique constructs mapping on to each category), through 2014

Ontology Category	Individual R/S Survey Items (N = 319)**	Unique R/S Constructs (N = 213)**
Religious or Spiritual Identity or Affiliation	*	*
Current Denomination or Affiliation of Self	11	3
Denomination or Affiliation of Family Members	8	6
Denomination or Affiliation Raised In	1	1
Self-Described Religiosity or Spirituality	10	8
Denomination or Affiliation of People you Spend Time With	4	4
Characteristics of Religious Community	*	*
Size of Religious Community	2	2
Religious Practices	3	3
Private Religious Practices	2	1
Private Prayer or Meditation	17	11
Private Reading of Holy Scriptures or Writings	3	3
Motivation for Private Religious Practice	7	2
Communal Religious Practices	8	5
Religious Meetings or Services	22	4
Communal Prayer or Mediation	1	1
Community Leadership	3	3
Service to Others	2	2
Faith-Based Group or Institution	8	6
Cultural Religious Practices or Norms	10	10
Religious Experiences	*	*
Belief or Conceptions of God or a Divine Being	6	6
Feel or Desire a Greater Union with God or a Divine Being	3	2
Feel Presence of God or a Divine Being	8	5
Conversion Experience	1	1
Religion as Source of Strength, Comfort, or Joy	17	9
Religious Discrimination	1	1
Struggle with Religious Beliefs or Conceptions of God or a Divine Being	5	5
Spiritual Experiences	1	1
Spirituality as Source of Strength, Comfort, or Joy	6	6
Spiritual Connection, Peace, or Harmony	13	8
Support	*	*
Religious Support	3	3
Spiritual Support	1	1
Quality of Relationships among Religious Community Members	22	22
Coping	11	8
Religious Coping	38	33
Spiritual Coping	6	5
Meaning	17	11
Forgiveness	1	1
Forgiving Self	2	2
Forgiving Others	3	2
Experience of Being Forgiven by God or a Divine Being	4	3
Gratitude	8	6
Centrality of Faith or Spirituality to One's Life	8	5
Religious or Spiritual Beliefs Affecting Medical Decision-Making	*	*
End of Life Decisions	5	5
Treatment Choices	1	1
Traditional Faith Healers	5	5
Spiritual Healing	10	8

* Although some parent categories have survey items or constructs mapped directly to them (instead of, or in addition to, survey items or constructs being mapped to their sub-categories), these parent categories do not have any survey items or constructs mapped to them, only to their sub-categories.

** Some R/S survey items and unique constructs map to multiple ontology categories, so each column does not add up to 319 and 213, respectively.

The R|S Atlas

BMJ Open

The R|S Atlas: Identifying Existing Cohort Study Data Resources to Accelerate Epidemiological Research on the Influence of Religion and Spirituality on Human Health

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The R|S Atlas: Identifying Existing Cohort Study Data Resources to Accelerate Epidemiological Research on the Influence of Religion and Spirituality on Human Health

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ABSTRACT

Objective: Many studies have documented significant associations between religion and spirituality (R/S) and health, but relatively few prospective analyses exist that can support causal inferences. To date, there has been no systematic analysis of R/S survey items collected in U.S. cohort studies. We conducted a systematic content analysis of all surveys ever fielded in 20 diverse U.S. cohort studies funded by the National Institutes of Health (NIH) to identify all R/S-related items collected from each cohort's baseline survey through 2014.

Design: An R|S Ontology was developed from our systematic content analysis to categorize all R/S survey items identified into key conceptual categories. A systematic literature review was completed for each R/S item to identify any cohort publications involving these items through 2018.

Results: Our content analysis identified 319 R/S survey items, reflecting 213 unique R/S constructs and 50 R|S Ontology categories. 193 of the 319 extant R/S survey items had been analyzed in at least one published paper. Using these data, we created the R|S Atlas (https://atlas.mgh.harvard.edu/), a publicly available, online relational database that allows investigators to identify R/S survey items that have been collected by U.S. cohorts, and to further refine searches by other key data available in cohorts that may be necessary for a given study (e.g., race/ethnicity, availability of DNA or geocoded data).

Conclusions: R|S Atlas not only allows researchers to identify available sources of R/S data in cohort studies, but will assist in identifying novel research questions that have yet to be explored within the context of U.S. cohort studies.

KEYWORDS

Cohort Study, Epidemiology, Religion, Spirituality, Ontology, Public Health, Relational Database, Health Disparities

ARTICLE SUMMARY

Strengths and Limitations of the study

- We conducted a systematic analysis of religion and spirituality (R/S) survey items collected by a group of 20 U.S. NIH-funded cohort studies to create a publicly available, online searchable database (R|S Atlas; https://atlas.mgh.harvard.edu).
- Cohorts included in R|S Atlas include diverse participant populations and contain a wide range of measures on clinical and health outcomes.
- R|S Atlas allows researchers to search for R/S items that are available in existing U.S. cohort studies and that could be used to conduct immediate prospective analyses.
- R|S Atlas will also assist in identifying novel R/S research questions that have yet to be explored within the context of U.S. cohort studies.

INTRODUCTION

Over the past 20 years, religion and spirituality (R/S) have been increasingly recognized as important resources for resilience that have both protective and deleterious effects on human health.[1, 2] Measures of R/S have been prospectively associated with several mental health outcomes, including reduced risk of depression,[3, 4] anxiety or emotional distress,[5] and risk of suicidal attempts.[6, 7] Prospective analyses of chronic disease risk have associated various measures of R/S with lower blood pressure and reduced risk of hypertension,[8, 9] cardiovascular events,[10] obesity,[11] mortality,[12-14] and higher self-rated health.[15-18] Multiple studies, including several randomized controlled trials, have shown that spiritual practices such as yoga and meditation increase expression of genes associated with enhanced mitochondrial function and insulin secretion, and reduce expression of genes linked to inflammation and the stress response.[19-22] Additional research is needed, however, to identify the mechanisms or pathways through which other dimensions of R/S may work to influence risk of disease.

Despite promising advancements, R/S research has been hampered by the relatively few high-quality prospective studies conducted with adequate sample sizes, the limited dimensions of R/S assessed, and the predominance of white, Christian study populations. A systematic review of studies published from 2000-2010 assessing R/S influences on depression, for example, found that only 45 of 339 extant studies were prospective, and several of these were rated as poor quality despite their prospective study design.[2] The relatively small number of prospective studies on R/S and health is due, in part, to a lack of R/S survey items routinely collected by U.S. cohort studies. Currently, very few cohort studies collect more than a few R/S items, and, when they do, a scientific rationale for item selection is often lacking.[23] Many R/S survey items collected by cohorts have also never been analyzed due to lack of

National Institutes of Health (NIH) funding in this area.[23] In 2019, R/S-related research received approximately 0.2% of all NIH research dollars spent.[a]

No study to date has systematically assessed which R/S survey items have been collected by U.S. cohort studies and are currently available to support prospective analyses of R/S influences on health. To address this gap in the literature and to facilitate prospective analyses investigating the influence of R/S on health, we: (1) conducted a content analysis of all surveys ever fielded by 20 NIH-funded U.S. cohort studies, in order to identify all R/S-related survey items fielded from each cohort's inception through 2014; (2) developed an R|S Ontology that maps all of the R/S items identified in our content analysis into a hierarchy of theologically meaningful conceptual categories; (3) conducted a systematic review to identify which of these R/S items have been analyzed in a published study; and (4) created R|S Atlas, a platform that organizes all of this information into an open-access, searchable, online research tool to facilitate prospective R/S analyses and advance understanding of the influence of R/S on the human health.

[a] Funding statistics were gathered using NIH RePORTER version 7.41.0 (https://projectreporter.nih.gov/reporter.cfm). Data are current as of April 18, 2020. Search terms used for R/S-related projects were:

Religion OR religious OR religiosity OR spiritual OR spirituality OR Buddhism OR Confucian OR Hindu OR Shinto OR Sikh OR Islam OR Muslim OR Judaism OR Taoism OR Daoism OR Bible OR church OR mosque OR synagogue OR ecumenical OR theology OR theological OR rabbi OR priest OR minister OR swami OR gurdwaras OR ashram OR pray OR prayer OR meditation OR worship OR God OR Allah

These terms were used to search all project abstracts and titles for fiscal year 2019. 171 R/S-related projects were awarded a total of $73,001,180 in 2019, compared with a total of $36,206,577,792 in 2019 NIH funding across 66,918 projects.

Note: the terms "Christian," "Jewish," "Jain," and "temple" were omitted because they retrieved projects unrelated to R/S with these terms in the names of hospitals, universities, and investigators listed.

METHODS

Selection of Cohorts

We generated a list of 35 NIH-funded cohort studies, prioritizing cohorts for inclusion in this list that represented diverse racial/ethnic communities (in order to support disparities-focused research), as well cohorts representing diverse clinical outcomes and large, national samples. Outreach to principal investigators (PIs) of these 35 cohorts was conducted until 20 PIs agreed to have their cohorts included in this analysis.

Content Analysis of Cohorts' Survey Instruments

All primary survey instruments, and as many ancillary instruments as possible, were collected from these 20 cohorts by use of study websites and/or assistance from cohort investigators. Surveys encompassed each cohort's first round of data collection through to their latest survey (through 2014), regardless of survey administration method (i.e., online, mail, or in-person) or population (e.g., the full cohort or a sub-population, such as an ancillary study). These surveys were then examined via a systematic content analysis to identify all R/S items ever administered in each cohort.

Research Assistants reviewed each survey instrument and recorded all survey items related to R/S, specifically looking for questions or response categories containing words or cognates of spirituality, religion, faith, God, higher power, divine, church, worship, Sabbath, prayer, congregation, clergy, priest, or meditation. Survey items were considered R/S in nature if the question, response category, or section header contained R/S-related content. The inclusion of each item, as well as the recorded contextual information related to each R/S survey item (e.g., source instrument, study population in which the question was fielded, full question, and response categories) and key cohort characteristics (e.g., year of inception;

sample size; composition of cohort by race/ethnicity, sex, age; and whether the cohort was geocoded and/or collected DNA samples) were checked by a second reviewer and any differences reconciled.

The basic unit of information extracted from cohort surveys to include as searchable items in R|S Atlas were individual R/S items from the surveys, regardless of format in which they were collected or asked. Depending on the cohort and the survey, an item might be a standalone measure, a sub-item from a larger scale, or a response category from a survey question (e.g., an R/S-related response category from a question asking the respondent to "mark all that apply"). Each R/S-related response category in a "mark all that apply" question was considered a different item to add to R|S Atlas. The same question asked to the same cohort population in multiple years was classified as a single item (users can see "Years Asked" information for each item within R|S Atlas to identify repeated items for each cohort). However, the same question asked by different cohorts, or even the same question asked to different groupings within the same cohort (e.g., a cohort's full exam vs. that cohort's ancillary study sub-population) were classified as separate individual items for the purpose of this content analysis. Likewise, questions similar in meaning but using different wording or response categories were also counted as multiple individual items. Classifying and counting survey items in this way was necessary in order to ensure that R|S Atlas conveys the full scope of R/S information collected and available in each cohort at the most granular level possible.

To allow researchers to understand the number of unique R/S constructs that each cohort has collected, however, we also collapsed groups of individual R/S survey items that are functionally identical or repeated (by the same cohort, different cohorts, or different cohort subgroups) into larger units of unique, non-overlapping constructs ("unique R/S constructs"). Examples of these unique R/S constructs include "How often do you attend religious services or organized religious activities?" (which combines individual R/S survey items such as "How often do you go to religious meetings or services?" or "How often do you attend church or other religious meetings?") and "What is your religious affiliation?" (which combines individual R/S

survey items such as “What religion would you identify yourself with?” or “What is your religious affiliation?”). Grouping items by unique R/S constructs provides a heuristic way to count units of information contained in R|S Atlas that are unique, non-overlapping R/S constructs. Additional work will need to be done to analytically harmonize the items within these unique constructs across cohorts prior to being used in analyses.

Development of the R|S Ontology

Based on our content analysis, and drawing from published literature and input from R/S and informatics experts, we developed an R|S Ontology that organizes the diverse R/S information we identified into theologically meaningful concepts and categories. As new R/S items were collected throughout our content analysis, we iteratively refined our R|S Ontology by mapping each R/S item onto our initial high-level concepts, and then adding, removing, or merging concepts in the R|S Ontology as needed so that all items would be captured by a category. We also created sub-categories (e.g., dividing “Coping” into “Religious Coping” and “Spiritual Coping”), where appropriate, to further refine the R|S Ontology. Throughout this process, input was provided by R/S and informatics experts and further adjustments made until all identified R/S items across all 20 cohorts were mapped onto theologically coherent categories and sub-categories in the R|S Ontology.

Systematic Review of R|S Atlas Items Used in Published Analyses

We then performed a systematic literature review (of articles published through 2018) for each R/S item collected in each cohort. We conducted a separate systematic review in PubMed for each item in the R|S Atlas using a search string that combined keywords from the item with the name of the cohort in which it was administered. All article titles and abstracts were screened from each search, and any article that included an item from the R|S Atlas as an

analysis variable was included in our final list. Articles were not screened further and excluded based on analysis type or study findings. No analysis of the content of the articles, beyond whether an R|S Atlas item was used as an analysis variable, was carried out. This process resulted in an exhaustive list of publications (if any) resulting from the collection of each R/S survey item in each of the 20 cohorts.

Development of the R|S Atlas Query Tool

Once all R/S items were identified from cohort surveys and classified according to our R|S Ontology, we incorporated them (along with the cohort data we had collected) into an online relational database called "R|S Atlas." To make this a functional and broadly useful tool, we worked with informatics and web design experts to develop R|S Atlas' foundational structure, search algorithms, and user interface.

Patient and Public Involvement

No patients or members of the public were involved in the design or recruitment of our study, nor in the dissemination of results.

Research Ethics Approval

As our research activities with the cohort studies were limited to content analysis of cohort survey questionnaires, this work is not considered human subjects research. Therefore, research ethics approval was not pursued or obtained.

RESULTS

Content Analysis

In total, we analyzed more than 200 survey instruments, representing thousands of pages and up to 67 years (1948-2014) of data collection. We identified a total of 319 R/S survey items across all cohorts, each of which is searchable in R|S Atlas as a discrete piece of information. The cohort collecting the most individual R/S survey items was the Adventist Health Study-2 (n=147), followed by the Hispanic Community Health Study/Study of Latinos (n=38). Aside from the religion-focused Adventist Health Study-2, only 172 R/S survey items have been collected across all of the remaining 19 cohorts. 13 cohorts collected 5 or more R/S survey items, and only 7 cohorts collected 10 or more items. After reviewing all R/S survey items for conceptual overlap, we arrived at a list of 213 unique R/S constructs collected across all cohorts. See **Table 1** for a complete list of participating cohort studies, their year of inception, and the number of individual R/S survey items and unique R/S constructs collected per cohort.

We identified 16 validated scales through our content analysis, represented (either in full or via selected sub-items used on surveys) by 193 R/S survey items. The scales most commonly represented by items in the R|S Atlas were the FACIT-Sp (n=41) and RCOPE (n=31). See **Table 2** for the validated scales represented in R|S Atlas (including citations and the number of R/S survey items and unique R/S constructs that relate to each scale).

Table 1. 20 Cohort Studies Participating in R|S Atlas (including the year each cohort began, and the number of R/S survey items and unique constructs collected), through 2014

Cohort Study Name	Year Initiated	Individual R/S Survey Items (N = 319)	Unique R/S Constructs (N = 213)
Adventist Health Study-2 (AHS-2)	2002	147	128
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Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO)	1993	1	1
Project Viva (Viva)	1999	3	3
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COPE[28]	2	2
Coping Strategies Inventory Short-Form (CSI-SF)[29]	1	1
Daily Spiritual Experiences (DSES)[30]	15	11
Duke University Religion Index (DUREL)[31]	8	6
Functional Assessment of Chronic Illness Therapy - Spiritual Well-being Scale (FACIT-Sp)[32]	41	25
Gratitude Questionnaire (GQ-6)[33]	6	6
Health Care Preferences Questionnaire[34]	2	2
JHS Discrimination (JHSDIS) Instrument[35]	2	1
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RCOPE[37]	31	29
Sabbath and Endtime Scale	20	13
Spiritual Meaning Scale[38]	5	5
Structure of Prayer[39]	9	9

R|S Ontology

The R|S Ontology comprises 50 concepts distributed across 12 high-level categories. Ontology categories most often captured by extant cohort R/S survey items were Religious Coping (n=38), Religious Meetings or Services (n=22), and Quality of Relationships among Religious Community Members (n=22). **Table 3** presents our final R|S Ontology and the number of R/S survey items and unique R/S constructs included in the R|S Atlas that map onto each Ontology category. As this table shows, many concepts have only rarely been asked in most cohorts.

Table 3. Structure of the R|S Ontology (including the number of R/S survey items and unique constructs mapping on to each category), through 2014

Ontology Category	Individual R/S Survey Items (N = 319)**	Unique R/S Constructs (N = 213)**
Religious or Spiritual Identity or Affiliation	*	*
Current Denomination or Affiliation of Self	11	3
Denomination or Affiliation of Family Members	8	6
Denomination or Affiliation Raised In	1	1
Self-Described Religiosity or Spirituality	10	8
Denomination or Affiliation of People you Spend Time With	4	4
Characteristics of Religious Community	*	*
Size of Religious Community	2	2
Religious Practices	3	3
Private Religious Practices	2	1
Private Prayer or Meditation	17	11
Private Reading of Holy Scriptures or Writings	3	3
Motivation for Private Religious Practice	7	2
Communal Religious Practices	8	5
Religious Meetings or Services	22	4
Communal Prayer or Mediation	1	1
Community Leadership	3	3
Service to Others	2	2
Faith-Based Group or Institution	8	6
Cultural Religious Practices or Norms	10	10
Religious Experiences	*	*
Belief or Conceptions of God or a Divine Being	6	6
Feel or Desire a Greater Union with God or a Divine Being	3	2
Feel Presence of God or a Divine Being	8	5
Conversion Experience	1	1
Religion as Source of Strength, Comfort, or Joy	17	9
Religious Discrimination	1	1
Struggle with Religious Beliefs or Conceptions of God or a Divine Being	5	5
Spiritual Experiences	1	1
Spirituality as Source of Strength, Comfort, or Joy	6	6
Spiritual Connection, Peace, or Harmony	13	8
Support	*	*
Religious Support	3	3
Spiritual Support	1	1
Quality of Relationships among Religious Community Members	22	22
Coping	11	8
Religious Coping	38	33
Spiritual Coping	6	5
Meaning	17	11
Forgiveness	1	1
Forgiving Self	2	2
Forgiving Others	3	2
Experience of Being Forgiven by God or a Divine Being	4	3
Gratitude	8	6
Centrality of Faith or Spirituality to One's Life	8	5
Religious or Spiritual Beliefs Affecting Medical Decision-Making	*	*
End of Life Decisions	5	5
Treatment Choices	1	1
Traditional Faith Healers	5	5
Spiritual Healing	10	8

* Although some parent categories have survey items or constructs mapped directly to them (instead of, or in addition to, survey items or constructs being mapped to their sub-categories), these parent categories do not have any survey items or constructs mapped to them, only to their the sub-categories.

** Some R/S survey items and unique constructs map to multiple ontology categories, so each column does not add up to 319 and 213, respectively.

R|S Atlas Items Analyzed in Previously Published Analyses

We identified a total of 104 publications that analyzed 193 R/S survey items contained in R|S Atlas. The greatest number of publications were related to the categories of Religious Service Attendance (N=39) and Religious and Spiritual Coping (N=23). The Adventist Health Study 2 (AHS-2) had the most R/S publications (N=18, assessing a total of 101 individual R/S survey items), while the remaining 19 cohorts published a total of 86 studies examining R/S survey items included in the Atlas.

R|S Atlas Query Tool

We integrated our R|S Ontology, cohort characteristics, and R/S items identified through our content analysis into an open-access data resource, R|S Atlas (https://atlas.mgh.harvard.edu). The R|S Atlas database is also archived permanently with more limited search functionality in the Harvard Dataverse (DOI: xxxx – we are still generating the DOI with Harvard dataverse, but will add the link in the paper proofs) The cohort is the unit of analysis represented in R|S Atlas. The R|S Atlas Query Tool search options include searching by keyword, searching via a Boolean drag-and-drop feature, and filtering results by keyword. Once searches are complete, users may also sort search results according to different criteria. The search functions provided by R|S Atlas are designed to help researchers identify which R/S items are available in which cohorts, so that they may contact those cohorts to request access to individual-level data.

The R|S Ontology, which forms the backbone of the R|S Atlas, provides a user-friendly way for investigators new to R/S research to find data, as they need not know the specific R/S terms that apply to their research; rather, they may simply select categories represented in the Ontology to search for survey items contained within that category. For example, selecting the Ontology concept of “Private Religious Practices” would retrieve many different types of survey

items; e.g., “How often do you pray” (BWHS); “I pray or meditate [Not at all, A little, Medium, a lot]” (NHS II); “How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?” (HCHS/SOL).

R|S Atlas also allows users to simultaneously cross-reference R/S survey items with demographic characteristics of cohorts (e.g., religious coping survey items administered in African American or female populations), and/or query a number of demographic (e.g., age, sex, or racial/ethnic composition) and other key cohort characteristics (e.g., availability of geocoded data or DNA samples). Lastly, the R|S Atlas Query Tool retrieves information from our literature review, which allows investigators to identify new, unstudied research questions for each Atlas item that could be immediately pursued.

The R|S Atlas website includes descriptions and links for each of the participating cohorts (via the “Cohorts” page) to facilitate investigators directly contacting individual cohorts that have the data they need to support their proposed analysis, and includes a “Resources” page that provides additional information and links on established scales represented in the Atlas, citations and links for cohorts’ publications that use R/S survey items in the Atlas, and links to some additional web resources related to R/S research.

DISCUSSION

Advancing knowledge regarding the role of R/S in health will likely require a two-pronged approach: (1) maximizing the usefulness of existing data to assess the influence of R/S on diverse health outcomes; and (2) persuading individual cohorts to collect additional R/S survey items to support prospective studies on a wider array of R/S variables. Our work, culminating in the development of R|S Atlas, helps address each of these challenges.

First, the searchable nature of R|S Atlas will help researchers identify existing R/S survey items that could be used immediately to conduct prospective studies investigating the influence of R/S on various clinical endpoints. R|S Atlas allows researchers to identify novel

analyses, focusing on unstudied R/S items, clinical outcomes, or cohort populations. R|S Atlas will also aid users in identifying R/S items available across several cohorts, which will facilitate comparative, pooled, or meta-analyses. For example, the R|S Atlas shows that NHS II, HCHS/SOL, MESA, and WHI are among the cohorts having collected a survey item on religious service attendance; investigators could therefore propose to conduct robust, comparative analyses on religious service attendance and health across a large and diverse set of white, Black, Hispanic/Latino, and Asian cohort participants.

Second, the relatively low number of different dimensions of R/S measured by this sample of 20 cohorts (**Table 1**) illustrates the need to expand the collection of R/S data in cohort studies in order to understand the complex ways in which R/S affect human health. R|S Atlas demonstrates that there are several important dimensions of R/S that are under-collected in U.S. cohorts (**Tables 2** & **3**). Survey items addressing more functional aspects of R/S, such as using positive religious coping, and even negative R/S experiences such as spiritual struggles and negative religious coping,[40-45] may be especially significant R/S influences affecting the etiology of disease that remain understudied.

This study has several limitations that should be noted. First, our cohort sample was not random. While the results may not be generalizable to all U.S. cohorts, our cohorts represent a variety of clinical conditions, racial/ethnic communities, and regions of the U.S. Second, while we are confident that our content analysis included all surveys of each cohorts' main study populations, cohorts varied in their ability to identify and provide survey instruments for past ancillary studies. Thus, some R/S survey items collected by smaller ancillary studies may not be included. Third, while we made efforts to include cohorts that represented diverse racial/ethnic communities, these 20 cohorts do not include all sub-populations in the U.S. (e.g., other American Indian sub-populations, Pacific Islanders). Fourth, the additional information we provide for each cohort (e.g., whether the cohort has geocoded data) is not exhaustive. Future efforts could expand the information provided on each cohort to allow more comprehensive

searches. Lastly, the information presented in R|S Atlas is only representative of cohort data collection efforts through 2014, although we have begun to add more current data.

Despite these limitations, our work represents the first systematic assessment of R/S survey items currently available within NIH-funded cohort studies, and addresses several barriers to better understanding the impact of R/S on health. R|S Atlas enables investigators to easily identify novel R/S analyses that could be conducted across multiple cohort studies. The R|S Ontology, constituting the conceptual structure of R|S Atlas, also facilitates harmonizing R/S survey items across cohorts, offering a framework for tracking and comparing items by conceptual category across additional cohort studies. Our hope is that R|S Atlas will facilitate additional high-quality, prospective studies of R/S and health in cohort study populations.

AUTHORS' CONTRIBUTIONS

ABS, BS, LM, and AES led the systematic content analysis. ABS, MAA, BS, LM, and AS developed the R|S Atlas database, with conceptual input from KIP and LU, and technical input from PT and ATM, on development and refinement of the ontology. BVK contributed to further refinements of the database and ontology categories after initial drafts were completed. MM created the R|S Atlas website and implemented all backend work on the website. ABS, MAA, MM, and AES contributed to the design and functionality of the website. ABS, MAA, BS, OI, BVK, and AES contributed to writing and developing the manuscript.

COMPETING INTERESTS

The authors declare no conflicts of interest.

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DATA SHARING

Aggregate, cohort-level data are available to search and download via the R|S Atlas website (https://atlas.mgh.harvard.edu). Individual-level data are available for analysis upon contacting the relevant cohort(s). Researchers will need to obtain ancillary study approval, execute appropriate data use agreements, and receive IRB approval (or equivalent) before individual-level data can be accessed from cohorts.

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