Family Caregivers and COVID-19: A Rapid Integrated Mixed Methods Systematic Review

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The Centers for Disease Control and Prevention (CDC) highlights the impact of infectious disease outbreaks on worsening mental health conditions, with increases in alcohol, tobacco and other substance/drug use[1,2]. The pandemic of COVID-19 emerged in China and spread rapidly worldwide. Its epidemic pattern of rapid spread, transmissibility, and a case-fatality rate of 2.3% has caused heightened fear and anxiety for the public[3]. The psychosocial impact of large quarantine measures, shortages of personal protective equipment, uncertain safe methods of handling dead bodies, and reduced access to routine care for individuals with pre-existing co-morbidities has contributed to an unprecedented public mental health crisis[2-5]. Psychosocial impacts extend beyond disease resolution[6] and populations at most risk include family caregivers who are caring for the most vulnerable.

Family caregivers/caregivers provide unpaid personal, psychological, physical, social and financial care[7,8]. Family caregivers provide unpaid care and are the backbone of the healthcare system; 28% of Canadians are current caregivers and 46% will be caregivers at some point in their lives. Over one-half (54%) of caregivers are women between the ages of 45 and 65 years[9]. Moreover, women are more likely than men to be healthcare workers on the frontline of COVID-19; globally women comprise 70% of the frontline workforce. Evidence suggests that women experience greater caregiving burden when they have multitasking difficulties or financial strain. Middle-aged caregivers manage multiple responsibilities, such as paid work, and unpaid family caregiving responsibilities in the home and in assisted/long-term care facilities (e.g., feeding, toileting family members). By 2035, the annual unpaid caregiver contribution to the Canadian health care system is estimated to be $128 billion. Family caregivers experience a significant amount of burden and distress[10], and during communicable disease outbreaks, families face an increased burden of care[11]. Shortages of healthcare workers and long waits in emergency departments push family members into primary caregiving roles for their loved ones; roles in which they lack adequate preparation and protection[11]. Family caregivers experience physical and mental exhaustion, insomnia, and anxiety/fear of being infected by loved ones. Caregivers perform duties with little protective equipment, balancing work with added caregiving responsibilities. In addition, when loved ones are admitted to hospital for treatment, caregivers are separated from their family member, when comfort and care is needed most. The overall goal of this rapid integrated mixed methods systematic review is to determine what is known about the mental health and wellbeing of family caregivers during communicable disease outbreaks.

METHODS
We are building on previous experience and expertise in knowledge synthesis[12-14] using methods described by the Evidence for Policy and Practice Information (EPPI) and the Coordinating Centre at the Institute of Education[15-19] to conduct a rapid integrated mixed methods systematic review of the literature. The first step in the EPPI review process involves a rapid broad mapping exercise to retrieve, screen and classify the published and unpublished evidence related to the mental health and wellbeing of family caregivers during communicable coronavirus outbreaks (e.g., severe acute respiratory syndrome [SARS-CoV], middle east respiratory syndrome [MERS-CoV], COVID-19). This broad

map exercise will be completed in first month of this rapid integrated mixed methods systematic review of the literature. The second step in the EPPI review process is to present and discuss the results of our broad mapping and screening exercise with collaborators (e.g., the Ontario Caregiver Organization), the investigative team (including men and women caregivers), national/provincial caregiver organizations, and other organizations interested in the mental health/substance use of family caregivers in a team meeting/consultation session. We will re-confirm priorities and search terms/strategies and ensure we are using language and addressing issues important to family caregivers living through COVID-19. The third step in the EPPI process is to conduct two-rapid parallel COVID-19 systematic syntheses. The first parallel syntheses will focus on bimonthly (i.e., every two months) systematic searches of the published/unpublished literature. The second parallel synthesis will focus on a systematic review of the grey literature. Both parallel syntheses will help us determine: 1) the mental health and wellbeing of family caregivers across ethnicities, ages, and sex/ gender, and 2) national and international resources, knowledge translation approaches, practices and platforms used to improve the mental health and wellbeing of family/unpaid caregivers during COVID-19.

Inclusion and exclusion criteria. The inclusion criteria for searching the published/unpublished and grey literature will be kept broad. The types of published/unpublished evidence will include guidelines, letters/editorials/text/opinion papers, cross-sectional studies, reviews, qualitative and cohort studies, randomized controlled trials, and mixed methods studies. Grey literature evidence will include surveys, news/commentaries/insights, policies/guidelines/position statements, financial resources, reports, websites, trial data, conference proceedings, and theses/dissertations. Participants will include informal or unpaid adult family caregivers over 18 years of age caring for adults or children. Types of outcomes included those related to psychological health (e.g., depression, anxiety, alcohol and/or substance use/misuse) during communicable disease outbreaks (SARS-CoV, MERS-CoV, COVID).

Search methods for identification of relevant evidence. Conventional search strategies of the published evidence will include sensitive searching and systematic screening using MeSH headings and textwords of the following databases: OVID Medline (1946 to present, including Epub Ahead of Print, and In Process & Other Non-Indexed Citations), OVID Embase (1947 to present), OVID PsycINFO (1806 to present), EBSCO CINAHL Plus with Full Text (1981 to present), Cochrane Central, Scopus, Web of Science, and the Native Health Database. Eligible studies from 2003 (outbreak of SARS) to the current date will be sought. Search strategies will be translated using each database platform's command language, controlled vocabulary, and appropriate search fields. MeSH terms, CINAHL headings, and textwords will be used for the search concepts of family caregiver, mental health/ substance use, and pandemics/coronavirus infections. A multi-strand approach will be used to search in Medline, Embase, PsycINFO, CINAHL, and Cochrane Central: search terms for family caregiver will be combined with the Boolean OR, search terms for mental health/substance use will be combined with the Boolean OR, and search terms for pandemics/coronavirus infections will be combined with the Boolean OR (strand 1). Finally, this query will be combined with terms for family caregivers and mental health/substance and pandemics/coronavirus infections using the Boolean AND. Search strategies in Scopus, Web of Science and the Native Health Databased will be simplified: concepts of family caregivers, mental health/substance use, pandemics/coronavirus infections will be combined with Boolean AND. We will apply a modified adult age filter to the Medline strategy[20]. This filter will then be translated and applied to Embase, PsycINFO, CINAHL, and Cochrane Central search strategies (Tables 1 and 2). We will then apply an English language filter and search from the publication year 2003 (outbreak of SARS) to the current search date. Unpublished COVID-19 literature will be searched using medRxiv, ClinicalTrials.gov, EPPI/Coordinating Centre COVID-19 living map of the evidence, Cochrane resources on coronavirus, Oxford COVID-19 evidence service, NICE rapid guidelines/summaries on COVID-19, McMaster COVID Plus, Elsevier, COVID-19 Open Research Database, Norwegian Institute of Public Health, and the WHO coronavirus disease pandemic

database[21] January 1, 2020 to the current search date. Search strategies of the unpublished literature will also be simplified: concepts of family caregivers, mental health/substance use, pandemics/coronavirus infections will be combined with Boolean AND. We will again only include evidence published in English. Selective and targeted searching of the grey literature will be guided by the Canadian Agency for Drugs and Technologies in Health (CADTH)[22], Ontario Public Health Libraries Association[23], and content knowledge experts (unpaid caregivers on investigative team, national/provincial caregiver organizations, and other organizations interested in the mental health/substance use of family caregivers invited to our second step team meeting/consultation session). We will begin targeted searching for national (i.e., Canadian) resources and then expand the search to international (i.e., United Kingston, Europe, United States, Australia) resources.

Selection of evidence. Published/unpublished citations will be exported/added to Endnote and imported into Covidence, a primary screening and data extraction tool used by Cochrane authors. Titles and abstracts will be screened in a first round and excluded if they do not refer to the psychological health (e.g., depression, anxiety, stress, alcohol and/or substance use/misuse) of family caregivers during communicable disease outbreaks (SARS-CoV, MERS-CoV, COVID).
A second round will be based on full-text screening. All titles, abstracts and full-text papers will be screened by two reviewers. Disagreements about published/unpublished paper inclusions will be resolved by either the nominated principal applicant (NPA) (MP) or the Co-Principal Applicant (Co-PI) (AKB). Grey literature sources will be searched and screened by two reviewers. A total of 10 reviewers (including patient partners/caregivers) will be available for screening the published/unpublished and grey literature. Weekly screening meetings and ad hoc consultations with the NPA (MP) and Co-PI (AKB) will help ensure screening accuracy and confirm understanding of the study inclusion and exclusion criteria.

Data extraction. Rapid data abstraction of the published/unpublished evidence will be done by all reviewers using a standardized data extraction form. The NPA (MP) will ensure data extraction accuracy by reviewing the published/unpublished evidence and the standardized data extraction form. Variables will include authors, title, year of publication, country, communicable disease, design, aim/objective (why), brief description (what), sample size, receiver of caregiving (e.g., child, parent, etc.), mental health and substance use description of carer, intervention (if present data extracted as per the Template for Intervention Description and Replication –TIDieR)[24], carer outcomes and measurement times, and other comments. As caregiving may differ for children, spouses/partners and older parents, for women and men, and across ethnicities; age, sex/ gender and ethnicity will be used as grouping variables when the data is extracted. Grey literature evidence will be extracted by reviewers using a separate national (i.e., Canadian) and international standardized data extraction form. Variables will include general and COVID-specific resources, knowledge translation approaches, practices and platforms used to improve the mental health and wellbeing of family/unpaid caregivers. All grey literature evidence will be reviewed by the NPA for consistency/accuracy.

Assessment of risk of bias in included published/unpublished evidence. Two reviewers will conduct independent risk of bias assessments of all published/unpublished evidence using critical appraisal tools recommended by the Joanna Briggs Institute[25].

Evidence Synthesis. We will complete a realist synthesis[26,27] and begin to apply findings of this rapid integrated mixed methods systematic review to the logic model of the Caregiver Support Framework[8]. This will include a description of the family caregivers (ethnicities, ages, and sex/ gender), mental health and wellbeing, and the national and international resources, knowledge translation approaches, practices and platforms used to during COVID-19. Cochrane Collaboration's Review Manager

Software (RevMan, version 5.4) will be used if a meta-analysis is possible. Methods recommended by the Joanna Briggs Institute[25] will be followed.

RESULTS

Rapid Broad Map of the Published and Unpublished Evidence (Step One). A total of 4,733 titles and abstracts were screened from the published/unpublished databases searches from 2003 to June 2, 2020; 365 papers were included for a full text review. Of these, 79 papers were included for data extraction (Figure 1). The majority of the papers were cross-sectional (n=34, 43%) or written as a letters/editorials (n=19, 24%). There were 12 reviews (15%), 10 (13%) qualitative publications, two (3%) mixed methods papers, one (1%) retrospective cohort study and one (1%) randomized controlled trial ([Link](https://drive.google.com/file/d/1mweYbj4EhNvR02r_g9Q8vSypcSzjnvQ_/view) to File, Copy Link to Browser: https://drive.google.com/file/d/1mweYbj4EhNvR02r_g9Q8vSypcSzjnvQ_/view). Most (n=47, 59%) focused on COVID-19 and were published in 2020. The majority originated from China (n=19, 24%) and the United States (n=19, 24%), only 13% (n=10) were from Canada. Eleven reviews were published (14%) in 2020, all focused on COVID-19. In addition, two guidelines/scientific statements published in 2020 were found. The NICE guidelines from the United Kingston focused on supporting adults who provide unpaid care for individuals over 16 years of age with health or social care needs. The American Heart Association published a scientific statement that synthesizes the evidence related to caregiving for adults with heart failure (United States). Both are silent on family caregiver needs/responses during pandemics.

Participants. When family caregivers were the focus of the paper, they were predominantly women (n=4176, 77%), aged 30 to 40 years. Seventy percent were married and most had at least an undergraduate degree. Almost 50% of the cross-sectional studies included a general population of respondents, so it was difficult to extrapolate the number of family caregivers within the broad sample. However, approximately 60% (n=64,953) of the participants in the general cross-sectional studies were women, 40 to 50 years of age; 30 to 70% had children and 50% were employed full time.

Settings. Family caregivers were primarily based in the community, despite some having family members (e.g., children, parents) in hospital or long-term care settings.

Outcomes. In the primary studies, depression and anxiety were most commonly measured using the Patient Health Questionnaire-9 (PHQ-9) and the General Anxiety Disorder-7 (GAD-7) scale. Self-reported stress appeared to be related to sex, age, education, and employment during the pandemic of COVID-19. Women generally experienced more distress ($\beta=-3.62$, p=0.000) than men and adults who suspended working reported higher distress than those who telecommuted ($\beta=-2.87$, p=0.012)[28]. The prevalence of anxiety and depression was higher in participants younger than 35 years compared to those participants who were aged 35 years or older ($p < 0.001$)[29]. Others report similar findings in that women who were under 35, underweight, primiparous, with a middle income were most likely to be depressed (a group of women not typically at risk)[30]. Being a housewife was also associated with depression (OR=1.35, CI 1.12-1.63), anxiety (OR=1.31, CI 1.11-1.55) and post-traumatic stress symptoms (OR=1.28, CI 1.11-1.47)[31]. Other predictors reported to cause poor mental health include being: 1) female, 2) less than 45 years of age, 3) more highly educated, 4) unemployed, and 5) in poorer health[32].

Team Meeting/Consultation Session (Step Two). The results of the rapid broad mapping exercise were presented and discussed with collaborators and investigators (including our patient partners/caregivers). National and provincial caregiving organizations and other organizations interested in the mental health/substance use of family caregivers were also invited to the team meeting/consultation session. Engagement occurred with knowledge users from the two Canadian provinces most affected by COVID-19 (Ontario-The Ontario Caregiver Organization, Quebec-L'Appui National) and others from the:

- Canadian Home Care Association/Carers Canada,
- Mental Health Commission of Canada,
- Family Caregivers of British Columbia,
- Caregivers Alberta,
- Caregivers Nova Scotia Association, and
- Canadian Cancer Society.

Priorities and search terms were confirmed to ensure breadth to an updated in-depth search of the published/unpublished and grey literature.

Two-Rapid Parallel COVID-19 Systematic Search (Step Three).

1. **Published/Unpublished Literature.** An additional 73 titles and abstracts were screened from the published/unpublished databases searches from June 2 – August 8, 2020. An additional 64 papers were included for a full text review and of these, 21 additional papers were included for data extraction (total of 100 studies from 2003 to August 8, 2020) (Figure 2). The majority of the papers were text/opinion papers (n=29, 29%) and cross-sectional descriptive studies (n=25, 25%). There were 18 reviews (18%), 13 (13%) qualitative publications, three (3%) cohort studies, two (2%) mixed methods papers, and one (1%) randomized controlled trial (Link to File, Copy Link to Brower: https://drive.google.com/file/d/1rVBFfJZLaIka1TCQzNDqbiSmxWrHaFpU/view). The majority originated from the United States (n=28, 28%), only 11% (n=11) were from Canada. No additional guidelines were found.

    Participants. Of the total 99,131 participants, 76,113 (77%) were women, aged 30-59 years.

    Settings. Family caregivers continued to be based in the community, despite some caregivers having family members (e.g., children, parents) in hospital or long-term care settings.

    Outcomes. Depression, anxiety, poor sleep, stress, fear, and symptoms of post-traumatic stress disorder were the most reported mental health outcomes. The Patient Health Questionnaire-9 (PHQ-9) and the General Anxiety Disorder-7 (GAD-7) scales were still the most commonly used reliable/valid reported measures for depression and anxiety. Smoking and alcohol use appeared to be related to higher levels of anxiety. Individuals with both high and low socioeconomic status appeared to have worse mental health outcomes; those with low socioeconomic status had financial strains and those with high socioeconomic status reported difficulty balancing work with child/elder care responsibilities. Migrants as women experienced symptoms of oppression that were linked to gender roles in the labor market and interpersonal power relations. Social isolation appeared to worsen mental wellbeing, and the level of burden increased after 4 weeks of quarantine. There were recommendations for:

    - Family and social welfare policies for individuals who are socially and economically marginalized,
    - Postpartum separation policies,
    - Flexible workplace policies,
    - Hospital and long-term care policies for caregivers as care providers, not as visitors,
    - Enhanced remote care that included telephone calls and online personalized interventions (Note: caregivers report feeling overwhelmed with the amount of available information),
    - Enriched strategies for virtual medicine,
    - Special training for volunteers and greater use of trainees to work with isolated elders and bereaved caregivers,
    - Crisis intervention supports, and

- Strategies that promoted self-compassion and self-awareness, acceptance, and communication.

2. **Grey Literature.** Our search of the national (i.e., Canadian) grey literature to determine the resources, knowledge translation approaches, practices and platforms used to improve the mental health and wellbeing of family caregivers during COVID-19 suggest there are a growing number of family caregivers in Canada who provide critical support to children, spouses, friends, and elders/parents. Women are more likely to feel stressed, anxious, depressed, isolated and lonely. Preparing meals, cooking, cleaning and disinfecting add more work, especially for women over 55 years-of-age. Visible minorities have increased their household work by an average of 3.5 hours/day during COVID-19 and caregivers who provide over 21 hours of care/week have more stress (Link to File, Copy Link to Browser: https://drive.google.com/file/d/1OljOVy6Ng15myU3N0pBElnaH-U2n58pQ/view). There is a range of resources in Canada for caregivers, these include:
   - Tips for caregivers of children, older adults, and people with varying levels of physical and mental abilities,
   - Resources published in multiple languages,
   - Support groups, respite/day programs, and professional services (Note: few caregiver support groups are specific to men despite the caregiving needs of men being recognized as being different from women[33]),
   - Advice on home schooling,
   - Information for Indigenous People,
   - General self-assessments and decision guides for family caregivers, and
   - Some financial resources that include caregiver benefits for critically ill children or adults, children with disabilities, and for children and adults at end-of-life.

Websites contain a breadth of resources for family caregivers, many appear complex and perhaps difficult to navigate for family caregivers experiencing symptoms of anxiety and/or depression. This is in line with previous research findings; caregivers often encounter challenges related to access to important information and needed services. Learning where to search for information and services and then being able to access them is often a demanding process for caregivers. Two provinces have developed a virtual assistant (i.e., Chatbot) to help users navigate and find information related to COVID-19. For example, when landing on the BC Government information webpage; the Chatbot "BC COVID Assistant" pops up, providing quick access by asking questions and receiving information without browsing through a lot of links and text. The Quebec Government webpage has a similar virtual assistant to help get information about COVID-19 but it does not appear as easy to find as the Chatbot on the BC webpage. Similarly, the Government of Canada "Benefits Finder" is a useful tool which helps caregivers quickly find benefit programs in which they may be eligible. After answering a few questions about their current situation, the tool provides general benefit and emergency programs tailored to COVID-19. It appears that the amount of information and online resources for family caregivers are emerging. However, there appears to be a lack of communication/coordination among some agencies, possibly complicating the search by family caregivers for information and resources.

Conclusions

At present, the evidence related to family/unpaid caregivers and COVID-19 is found primarily in text/opinion papers and in cross-sectional study designs. There still remains very few randomized controlled or mixed methods study designs. Quality assessment of the published/unpublished literature

needs to be undertaken before evidence synthesis and recommendations can be made. Many studies did not examine family/unpaid caregivers exclusively. The unpaid care of family caregivers was rarely visible, and often subsumed under the guise of the paid carer undertaking multiple roles. All Canadian provinces provided online information of federal, territorial and local products and services that were available to caregivers. It is however not clear how effective the knowledge translation approaches have been in facilitating information exchange for family caregivers. Often the information on websites was embedded in more general information for patients and health care users; we are uncertain if the family caregivers were able to use the online information sources effectively. Further research is needed to clarify the effectiveness of these online tools by family caregivers and to determine if other international knowledge translation approaches, practices and platforms are used to improve the mental health and wellbeing of family caregivers during COVID-19.

Of the COVID-19 cases reported in Canada, 50% are women; 66% of cases are 40 years of age and over (Government of Canada, June 26 2020). A recent report (May 2020) from The Ontario Caregiver Organization indicates caregivers under 65 years of age are coping worse mentally and emotionally compared to those caregivers over 65 years of age. The economic implications of a distressed middle-aged work force balancing unpaid care with paid work is very real; results may be devastating if we do not properly identify and manage the mental/emotional health of the family/unpaid caregiver.

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Table 1. MeSH headings.

"Family Carer"	"Mental Health and Substance Use"	"Coronavirus infections/pandemics"
1: MH "Caregivers"	1:MH "Mental Health"	1:MH "Pneumonia, viral"
2: MH "Caregiver"	2:MH "Health, Mental"	2:MH "Coronavirus Infections+"
3: MH "Carers"	3:MH "Mental Hygiene"	3:MH "Pandemics"
4: MH "Carer"	4.MH "Hygiene, Mental"	4.MH "2019 Novel Coronavirus Disease"
5: MH "Care Givers"	5.MH "Mental Disorders+"	5.MH "COVID19"
6: MH "Spouse Caregivers"	6.MH "Anxiety Disorders+"	6:MH "COVID-19 Pandemic"
7: MH "Caregiver, Spouse"	7.MH "Bipolar and Related Disorders+"	7.MH "SARS-CoV-2 Infection"
8: MH "Caregivers, Spouse"	8.MH "Disruptive, Impulse Control, and Conduct Disorders+"	8.MH "COVID-19 Virus Disease"
9: MH "Spouse Caregiver"	9.MH "Feeding and Eating Disorders+"	9. MH "2019 Novel Coronavirus Infection"
10:MH "Family Caregivers"	10.MH "Mood Disorders+"	10.MH "2019-nCoV Infection"
11.MH "Caregiver, Family"	11.MH "Neurocognitive Disorders+"	11.MH "Coronavirus Disease 2019"
12.MH "Caregivers, Family"	12.MH "Neurodevelopmental Disorders+"	12.MH "Coronavirus Disease-19"
13.MH "Family Caregiver"	13.MH "Neurotic Disorders"	13.MH "2019-nCoV Disease"
	14.MH "Personality Disorders+"	14.MH "COVID-19 Virus Infection"
	15.MH "Psychotic Disorders+"	15.MH "Middle East Respiratory Syndrome Coronavirus"
	16.MH "Trauma and Stressor Related Disorders+"	
	17.MH "Sleep Wake Disorders+"	
	18: MH "Substance-Related Disorders+"	

Table 2. Textwords.

"Family Caregivers"	"Mental Health and Substance Use"	"Coronavirus infections/pandemics"
Primary Carer	Alcoholism	SARS
Primary Caregiver	Binge Drinking	Severe Acute Respiratory Syndrome
Unpaid Carer	Drug Overdose	Swine
Unpaid Caregiver	Drug Abuse	Disease Outbreaks
Informal Caregiver	Drug Use Disorder	COVID-19
Domestic Partner(s)	Illicit Drugs	MERS
Care Giver	Alcohol-Related Disorders	Middle East Respiratory Syndrome
Married Persons	Addiction	
Wife	Marijuana Abuse	
Husband	Alcohol Intoxication	
Sibling	Substance Abuse	
Parent	Tobacco Use	
Mother	Inhalant Abuse	
Father	Cocaine Use	
	Narcotic Disorders	
	Organic Mental Disorders	
	Prescription Drug Abuse	
	Substance Dependence	
	Substance-Induced Psychoses	
	Withdrawal	
	Paranoia	
	Paranoid	
	Depression	
	Adjustment Disorder	
	Acute Distress Disorder	
	Psychological Distress	
	Situational Disturbance	
	Reactive Disorders	
	Behavior Disorders	
	Sleep Disorder	
	Eating Disorders	
	Dyssomnia	
	Parasomnia	
	Affective Disorders	
	Mood Disorders	
	Psychoses	
	Personality Disorder	
	Passive-Aggressive	
	Feeding Disorders	
	Anxiety Disorders	
	Moral Distress	
	Social Isolation	
	Loneliness	
	Caregiver Fatigue	
	Caregiving Fatigue	
	Financial Worry	

| | Lack of Self-Care
Role-Related Stress/Role Stress
Work-Related Stress/Work Stress
Secondary Psychological Distress
Panic
Worry
Fear
Grief
Post-Traumatic Stress Disorder
PTSD | |

Figure 1. Published/Unpublished PRISMA Flow Diagram (Rapid Broad Map, 2003 – June 2, 2020).
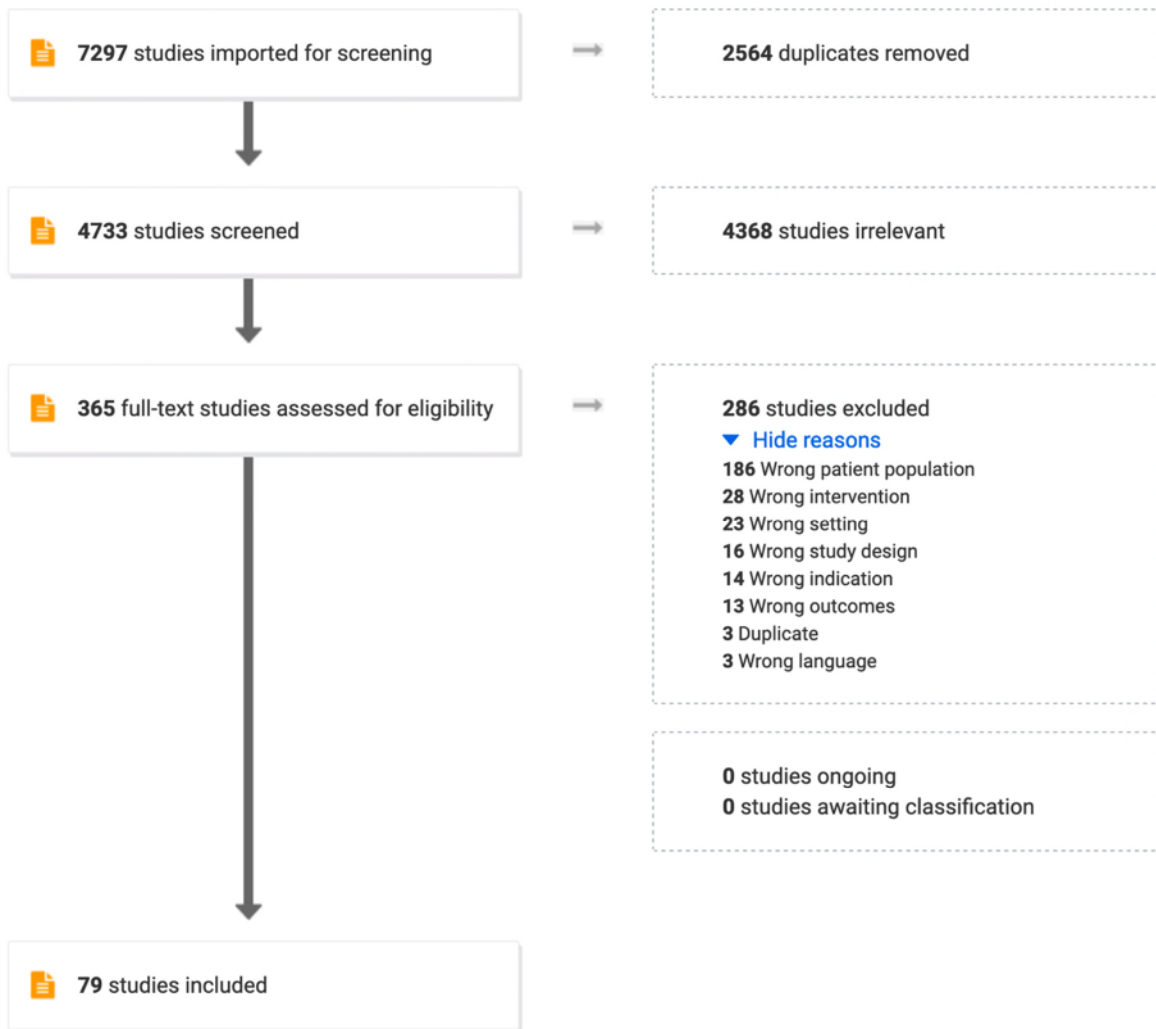
Figure 2. Published/Unpublished PRISMA Flow Diagram (Rapid Parallel Search, 2003 – August 8, 2020)