

A systematic review and thematic synthesis of the experiences of living within PFAS-polluted environs

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Citation

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Review question

The review will have a broad focus, aiming to thematically synthesize experiential, qualitative accounts relating to living with PFAS using a thematic approach. Therefore, the overarching question of the review will seek to answer:

How does living with PFAS influence the lives of people within fenceline communities and chemical industry workers, from their own perspectives, the chemical industry, their supporters, and relevant government officials including health, and social care professionals?

Searches

This systematic review will assess published mixed method and qualitative studies with the aim of thematically synthesizing evidence from multiple types of research and sources. The review will also incorporate unpublished grey literature, specifically electronic resources, written by the government, chemical industries, NGOs/CSOs, and health institutions. Select databases will cover a range of public health, medical, behavioral, social, and psychological research, capturing a range of relevant disciplines. These include MEDLINE OVID, Cochrane Central, Web of Science, Scopus, and Regular Google grey literature.

An Embase search strategy was developed and will later be adapted for the other databases. Search terms were developed relating to the following groups:

1. PFAS exposure (e.g. PFAS*, PFOA, PFOS, Perfluor*, Polyfluor*, Fluorotelomer*)
2. Exposure pathways (e.g. 'water contamination'/exp, 'soil pollution'/exp, 'air pollution'/exp, 'food contamination'/de)
3. Study methodology (e.g. interviews, questionnaire, and focus groups)
4. Lived experiences of workers (e.g. 'occupational exposure'/de, 'occupational disease'/de, 'biological monitoring'/de), 5. Lived experiences of fenceline communities (eg. biomonitor* OR (fence-line*, fenceline*, surrounding*))

Specificity and sensitivity to the search were balanced with reference to the topic, and where appropriate, synonyms, subject headings, and spelling differences were included, to comply with development guidelines for a robust search strategy.

The initial search strategy will be further refined to ensure that we maximize the search input before conducting the actual search.

Types of study to be included

The type of study will be mixed methods with a qualitative component or purely qualitative analysis of the effects and experiences of living with PFAS. It will extract opinions and perspectives of PFAS fenceline communities, PFAS company workers who directly work in the PFAS production and manufacturing plants/factories, various chemical industries, relevant government officials, supporters of people living with PFAS, chemical industry officials, health experts, and social care health professionals. The envisaged research types are either focus group discussions, interviews, ethnography, or other qualitative research methodologies.

Secondary data from related systematic reviews, discussions, narrative reviews, opinion pieces, meta-synthesis, meta-analyses, and opinions, will not be incorporated into the review. The secondary data will be analyzed separately to inform the research direction and as input to the introductory and discussion sections. Primary data in the form of quantitative studies, opinion pieces, and discussions, will be excluded.

Condition or domain being studied

The primary focus of the review is to thematically synthesize the experiences of fenceline communities and chemical industry workers living with PFAS and its health, social, behavioral, and psychological impacts. People outside fenceline communities or not working within the chemical industries will not be included. Papers involving people with no determined health effects from PFAS will be included due to the social, behavioral, and psychological impacts of living close to the chemical industry. The search strategy includes terms relating to PFAS exposure, exposure pathways, study methodology, and lived experiences of both the communities and chemical industry workers.

Participants/population

This review focuses on lived experiences within PFAS-polluted environs, from the perspectives of fenceline communities and chemical industry workers, their supporters, health, and social care professionals, as defined below. Defining participants/population clarifies the scope and refines the inclusion and exclusion criteria.

Fenceline communities: Families who live close to a particular PFAS production or manufacturing chemical industry and who are described as living with PFAS and its known effects. Clinical diagnostics are not a pre-requisite, to avoid the exclusion of relevant articles focused on non-medical related effects. Even though PFAS affects the general population the research will be limited to fenceline communities.

Chemical industry workers: Workers in PFAS production or manufacturing chemical industries that produce toxic chemicals like PFOA, PFOS, Genx, etc that work/worked in PFAS production and manufacturing plants.

Supporters: Family, friends, NGOs/CSOs, or lay / unpaid caregivers of people living with PFAS.

Chemical industries: companies that either manufacture PFAS or use it in the production of products.

Government, health, and social care professionals: Government institutions supporting people living with PFAS, occupational health workers, social workers, nurses, paid caregivers, specialized medical doctors, general practitioners, psychologists, occupational therapists, and other clinicians who provide care for people living in with PFAS.

Intervention(s), exposure(s)

The review aims to gather qualitative data relating to the experiences of living with PFAS by fenceline communities and chemical industry workers. All relevant evidence will be included.

Comparator(s)/control

As part of this review, the views of fenceline communities living with or workers exposed to PFAS will be

compared/contrasted with the views of various chemical industries, government officials, health providers, supporters, and social care professionals, in order to gain a fuller understanding of their experiences, identify further gaps, as well as discuss differing perceptions. Comparisons will not be conducted between the fenceline community exposure and the general public or the exposed workers with the non-exposed worker communities.

Context

Compiling evidence on the lived experiences of fenceline communities and chemical industry workers is a global need. Thus far, scholarly research on the psychosocial health effects of working or living near the PFAS chemical industries or PFAS contaminated areas is scattered in scientific publications, and unpublished grey literature. Several studies at local level expressed residents and worker concerns relating to physical health, the future health of their children, psychological problems (stress and anxiety) and socio-economic impacts. There is not yet a formal systematic review on lived experiences of PFAS fenceline communities and workers.

This systematic review will synthesis evidence from multiple sources regarding experiences of people working, living, or owning property in PFAS contaminated zones or manufacturing plants. Our aim is to increase understanding on worker and fenceline community perceptions of physical and psychosocial health and other social concerns, on a global scale. This formal systematic review is part of the larger PFAS research project titled: Understanding the history and contemporary dynamics of PFAS Ecotoxicity by talking to those who have experienced it.

Relevant research stresses the need to synthesize personal experiences and stories, so as to gain more knowledge on the current state of affairs, key issues, emerging themes and possible recommendations. The review will also consist of a thematic synthesis of an array of behavioral, social, psychological and health related research, and the lived experiences associated with PFAS exposure. Findings may provide a basis for application of a research, practice and / or policy framework.

Main outcome(s)

An initial analysis of existing primary data indicates that the range of PFAS-related effects and lived experiences varies considerably. Most studies focus on health-related outcomes, which will not be the main focus of this review unless the research uses qualitative methodologies to extract data from key stakeholders, including the persons exposed to PFAS. Other established effects range from behavioral, cognitive, social, and functional. The review is expected to cover an array of outcomes including access to services (health, social care, remediation, legal), anxiety, depression, apathy, place attachment, neglect, safety, social networks, engagement or isolation, and how these effects impact on their work, family and home.

Measures of effect

Not applicable.

Additional outcome(s)

None.

Measures of effect

Not applicable.

Data extraction (selection and coding)

EndNote 20 is the select reference management software. The Endnote library will be shared with the entire review team to facilitate collaboration. Article screening, appraisal, and data extraction will be conducted using Covidence.

The first process is importing references into EndNote for pdf extraction and de-duplication. After duplicate removal, the final outputs will then be imported to Covidence. Two reviewers will blindly screen the titles and abstracts, to

establish their relevance based on pre-determined exclusion and inclusion criteria. Each excluded article will be supported by a brief note explaining the reason(s) for its exclusion. If any discrepancies or conflicting results arise, the article will be screened by a third reviewer, for relevance. The third reviewer's decision will be final.

Reading of full texts of relevant literature will be undertaken by two researchers, to decide whether they qualify to be included in the final list of publications that will undergo the thematic synthesis. Excluded articles will be accompanied by a note that outlines the reason(s) why it was excluded.

A data extraction spreadsheet will be created. The spreadsheet will contain the following information: study objective/aim, demographics, place of study, qualitative methodology/ies used, data collection, approach used to synthesis the data, emerging themes, study outcomes, key respondent quotations, research, policy and practice-related findings, study limitations, author recommendations, and conclusions.

Risk of bias (quality) assessment

Each of the final articles will undergo a quality assessment using an established critical appraisal checklist, such as the Consolidated Criteria for Reporting Qualitative Research (COREQ) tool, the Critical Appraisal Skills Programme (CASP), or the Standards for Reporting Qualitative Research (SRQR) tool. The final tool selection will be guided by the nature of the included research and the various study designs. If needed, two or more tools will be combined to develop customized criteria to assess the study. Two reviewers will be involved in the quality assessment and if in conflict a third reviewer will make the final decision. The rigor and reliability of the results of the assessment will be achieved by establishing a minimum quality threshold.

Strategy for data synthesis

The planned meta-synthesis seeks to increase understanding of living with PFAS amongst fenceline communities and chemical industry workers to advance research, inform social care and health policy, and recommend changes in current practice. The adopted approach is thematic synthesis, consisting of three stages: text coding, developing descriptive themes, and finally the extraction of analytical themes (Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, 8(1), 1-10.).

The thematic synthesis will be conducted as follows:

Text coding: First the reviewers will extract from the results section of each article the raw qualitative data, including second-level interpretations by authors. This data will be stored in a shared Atlas.ti database. The primary data will include perceptions and experiential accounts of PFAS-related effects. Two researchers will conduct independent free coding - sentence by sentence, and if necessary, they could assign multiple codes (per sentence). Free coding will facilitate the development of new codes or the reuse of existing codes, throughout the review process. Verification of consistency of the coded text will be done by the entire research team during consecutive group meetings.

Developing descriptive themes: The second phase starts with the hierarchical arrangement of the free codes. Results will be visualized using tree structures showing multiple code layers. Hierarchical arrangement and visualization will inform the process of developing descriptive themes. For instance, a code relating to access to health care may have a sub-layer code on free PFAS blood testing and a further sub-sub-layer on anxiety related to test results. Descriptive themes are limited to the content in the select review articles.

Extracting analytical themes: Once the review team agrees on the descriptive themes, these themes will be expanded to extract analytical themes. Analytical themes are more abstract than descriptive themes and their generation is not limited to the content of the included review documents. Extraction of analytical themes will be conducted through a cyclical process until all descriptive themes are synthesized. The review team comprises of PFAS experts, systematic review experts and persons with working knowledge of the meta-synthesis methodology. This will facilitate a rigorous review process, which is unbiased and results in high-quality synthesis of research findings.

Analysis of subgroups or subsets

Findings for fenceline communities, PFAS chemical industry workers, their supporters, chemical industry, health workers, relevant government officials, and social care professionals will be separately extracted, and cross-compared to identify emerging subgroup similarities and differences. The extent of implementing this planned analytic approach will highly depend on the available primary data.

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Type and method of review

Synthesis of qualitative studies, Systematic review

Anticipated or actual start date

16 January 2023

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31 July 2023

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Conflicts of interest

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Netherlands

Stage of review

Review Ongoing

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Subject indexing assigned by CRD

Subject index terms

MeSH headings have not been applied to this record

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22 January 2023

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11 January 2023

Stage of review at time of this submission

The review has not started

Stage	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

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