



**Patient navigation for people with
dementia, their caregivers, and
the care team: A scoping review**



Executive summary

Our team conducted a scoping review to explore the characteristics of patient navigation programs for people with dementia, their caregivers, and/or members of the care team. Scoping reviews are useful because they evaluate and summarize all available information on a particular topic. They combine a range of sources and study designs to summarize available information to inform practice, policy, or programs. They can also provide direction for future research. Scoping reviews are useful for answering broad questions.

For our scoping review, we asked:

What are the characteristics of patient navigation programs that have been reported in the literature to support people with dementia, their caregivers, and/or members of the care team?

How we did this scoping review:

This review was conducted using the Joanna Briggs Institute methodology for scoping reviews. The general steps are identifying the research question; identifying relevant studies; study selection; charting the data; and collating, summarizing, and reporting the results.

We included studies that were about patient navigation programs for people with dementia, their caregivers, and/or members of the care team. We included publications that described any navigator title and any setting. We included all types of study designs as well. We excluded reviews, like systematic reviews; however, we hand searched the reference lists of relevant reviews. We also excluded studies published before 1990 and articles about case management.

We designed a search strategy which included five databases and a grey literature search. Grey literature is information that is produced outside of traditional publishing channels. We used a software called Covidence to go through the 5,198 results found by the search strategy. At the end of the screening process, we had a total of 45 articles, which described 24 different programs.

We found:

Most of the articles were published in the United States and between 2015 and 2020. Other locations included Canada, the United Kingdom, Australia, New Zealand, Norway and Denmark.

The services provided varied across programs. All the patient navigation programs provided some form of referral and/or linkage to other services, resources, or care. Most of the programs included the provision of education to people with dementia and their caregivers, either in the form of courses or tailored educational and informational resources.

A number of articles reported on team composition. Most teams were interdisciplinary and included nurses, pharmacists and unlicensed lay navigators. There were also teams made up exclusively of clinical workers and teams of only non-clinical lay workers.

The majority of programs were implemented in a community setting, such as homes or municipal resource centers. Other programs were implemented in clinical settings, such as primary care clinics.

There was no standard or universal delivery method for patient navigation programs. The methods of delivery included in person, telephone-based, web-based, or combinations of these. The most common delivery method was a combination of phone and in-person. Notably, even within programs, there was no consistent communication method reported.

There was also no standard navigator title. The most common was care coordinator. Most titles had some variation on “coordinator”, “navigator” or “consultant”.

Most programs only served people with dementia, but a few also served people with cognitive impairment or a cognitive disorder as well. A few articles reported programs having age requirements, which ranged as low as 45 years old to as high as 70 years old. Some programs reported other eligibility requirements, such as clients be living at home and in the community, clients be veterans, and clients be enrolled in the program alongside their caregivers.

The most commonly listed facilitator for patient navigation programs was collaboration and communication between key stakeholders, as well as formal partnerships between healthcare and community organizations. Another common facilitator was flexible and adaptable delivery models that allowed frequent and flexible communication with clients. Other facilitators included logistical and administrative tools, like shared data bases and computer systems, and cost effectiveness. Common barriers included burnout for navigators and difficulties coordinating with key partners and partnering organizations. Other barriers included difficulties recruiting clients, identifying resources for low-income clients, and the need for space for records and administrative support.

Summary and conclusion:

This information provides insight into how patient navigation programs for people with dementia and their caregivers are put into operation and implemented. This information may be useful for individuals and organizations looking to implement their own programs in the future, and it will also provide a framework for future systematic reviews seeking to evaluate the effectiveness or efficacy of dementia navigation programs. This document was a summary of a scoping review’s results, which you can read about in full when it is published.