Barriers in Health and Social Care Access and Navigation for Elder Orphans:
A Scoping Review of the Literature

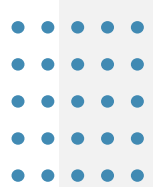Lucy Kervin,[1] Indira Riadi,[1] Kelly Teo,[1] Ryan Churchill,[1] Theodore D. Cosco[1,2]

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Presentation Overview

- Background/Context
- Objective/Choice of Methods
- Scoping Review Methodology
- Developing the Research Question and Strategy (PCC)
- Criteria for Study Eligibility
- Information Sources
- Screening
- Overview of Search and Selection
- Planned Structured Extraction & Synthesis
- Results
- Preliminary Comments and Thoughts

Background: A Growing Vulnerable Population

- Family members have traditionally supplied informal care in later life.
  (personal care, minor medical procedures, administrative tasks, social and emotional support)[1]

- Social and demographic trends are shifting familial support availability for older adults both locally and globally.
  (family mobility, divorce/stepfamily formation, declining fertility, intergenerational ambivalence)[2,3,4]

- A 'call to action' Carney et al. (2016)[5]

ELDER ORPHANS

"Aged, community-dwelling individuals who are socially and/or physically isolated, without an available known family member or designated surrogate or caregiver."

'Unbefriended' patients[6]
- Lacking both capacity to make one's own informed health decisions + surrogate

Objective & Choice of Methods

Traditional Systematic Review
- Applied within health research to assess the effectiveness/experience of interventions.[7]
- **Incongruous** with <u>broad</u> health care delivery research questions best answered through exploring wide range of evidence.[7]

What we wanted to find out:

"What are the barriers encountered by older adults aging without familial/informal support, or elder orphans, in accessing needed services and navigating current health and social care systems?'

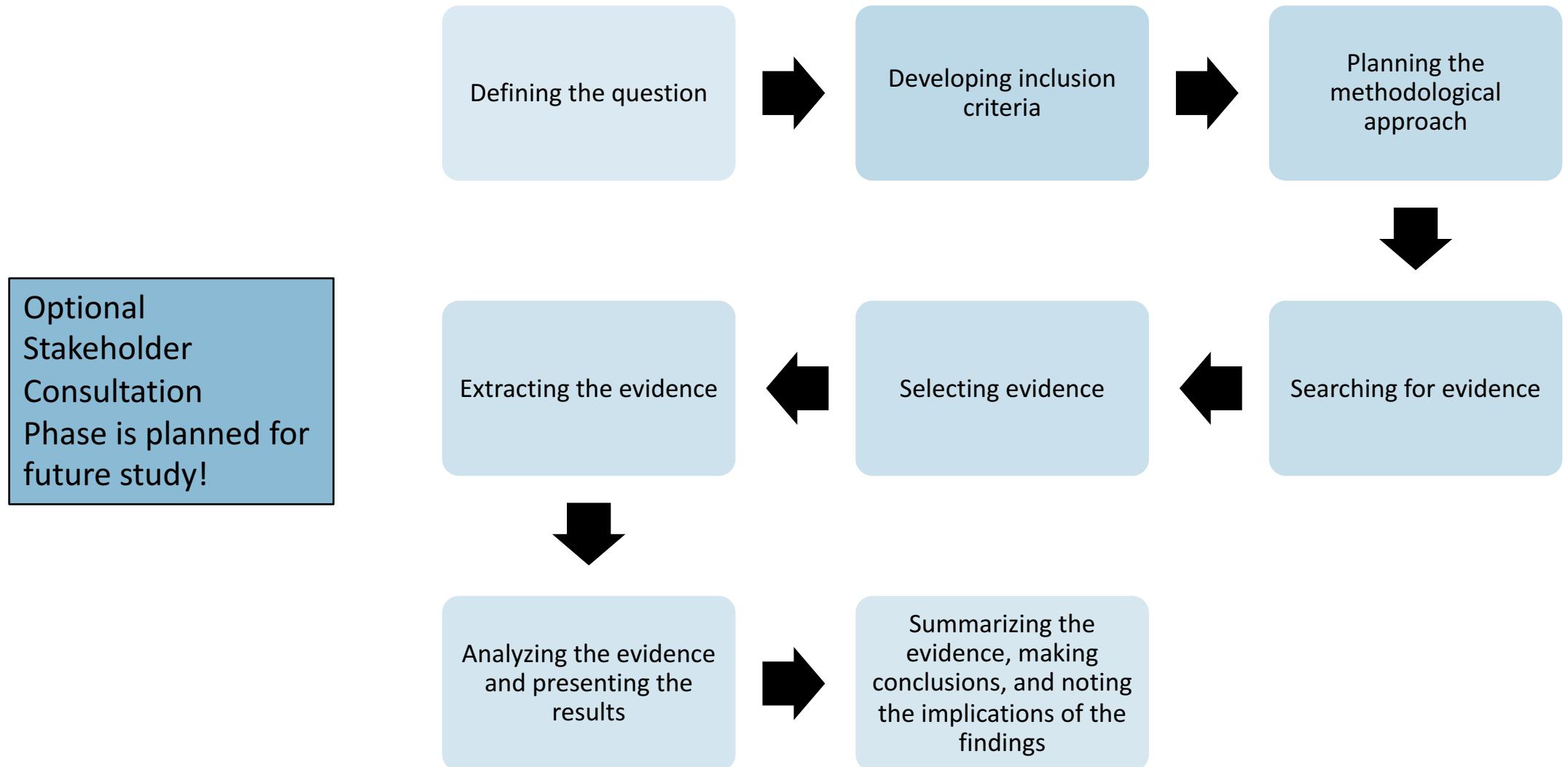"What are potential facilitating factors in identifying and addressing this population's barriers in accessing defined services?"

Why a Scoping Review?

- Methodologically rigorous approach for exploring topics that are emergent, complex and/or diverse, have yet to be comprehensively reviewed.[7]

- Enables review and synthesis of studies of various methodologies (quantitative, qualitative, mixed methods).[8]

Scoping Review Methodology (Arksey & O'Malley)[9]

Defining the question → Developing inclusion criteria → Planning the methodological approach ↓

Extracting the evidence ← Selecting evidence ← Searching for evidence

Optional Stakeholder Consultation Phase is planned for future study!

Analyzing the evidence and presenting the results → Summarizing the evidence, making conclusions, and noting the implications of the findings

Research Question and Search Strategy 'PCC'[10]

Population

Isolated older adults without familial/informal support

"elder* orphan*", "adult orphan*", "orphan* older person", "solo age*", unattached older adult*", never married older adult*", "unbefriended older adult*" kinless older adult*", "unbefriended elder*, "isolated older adult*", "isolated elder*", "ageing alone"

Concept

Barriers/facilitators in navigation/service access

"barrier*", "factor*", "challenge*", "obstacle*", "attitude*", "perceive*", "perception*", "opinion*, "belief*", "knowledge", "implement*", "facilitate*", "disparit*", "access*", "need*", "usage", "deliver*", "util*", "access*", "inacces*", "provision*", "availab*", "prohibit*", "affordab*", "applicab*", navig*"

Context

Health/social care and services

"health", "healthcare", "health care", "primary care", "secondary care, "tertiary care", "emergency care", "community healthcare", "service*", "program*", "resource*", "treatment*", "intervention*", "strateg*", "refer*", "consult*", "social care". "social work*", :home care", "voluntary care service*", community care", social service*"

Criteria for Eligibility

Inclusion	Exclusion
••Reference to barriers and/or facilitators to navigation of health and/or social care services and systems by the population of interest ••Date of publication 01/2005 – 02/2021* ••Publication in English ••Peer-reviewed full report of study ••Inclusion of participants age 65+ who are identified as being without access to informal/familial support, are social and/or physically isolated and are living within the community.	••Non-human studies ••Non-primary studies (ex. Review articles, commentaries, conference abstracts, theses or dissertations) ••Studies involving only participants whose primary residence is an environment providing impromptu access to 24/hr care.** ••Studies focusing only on any other age groups or only care professionals.***

Term 'elder orphan' first arose in early 2000s in lay press,[11,12] nursing journal in 2005[13]

** *Enables more meaningful synthesis of smaller # of relevant studies, facilitates identification of barriers experienced while community-dwelling which may (in part) lead to early institutionalization.*

****Studies with both E.Os and other populations were included if findings specific to EOs could be clearly identified and extracted.*

Methods: Information Sources

Pilot Search (keyword identification)

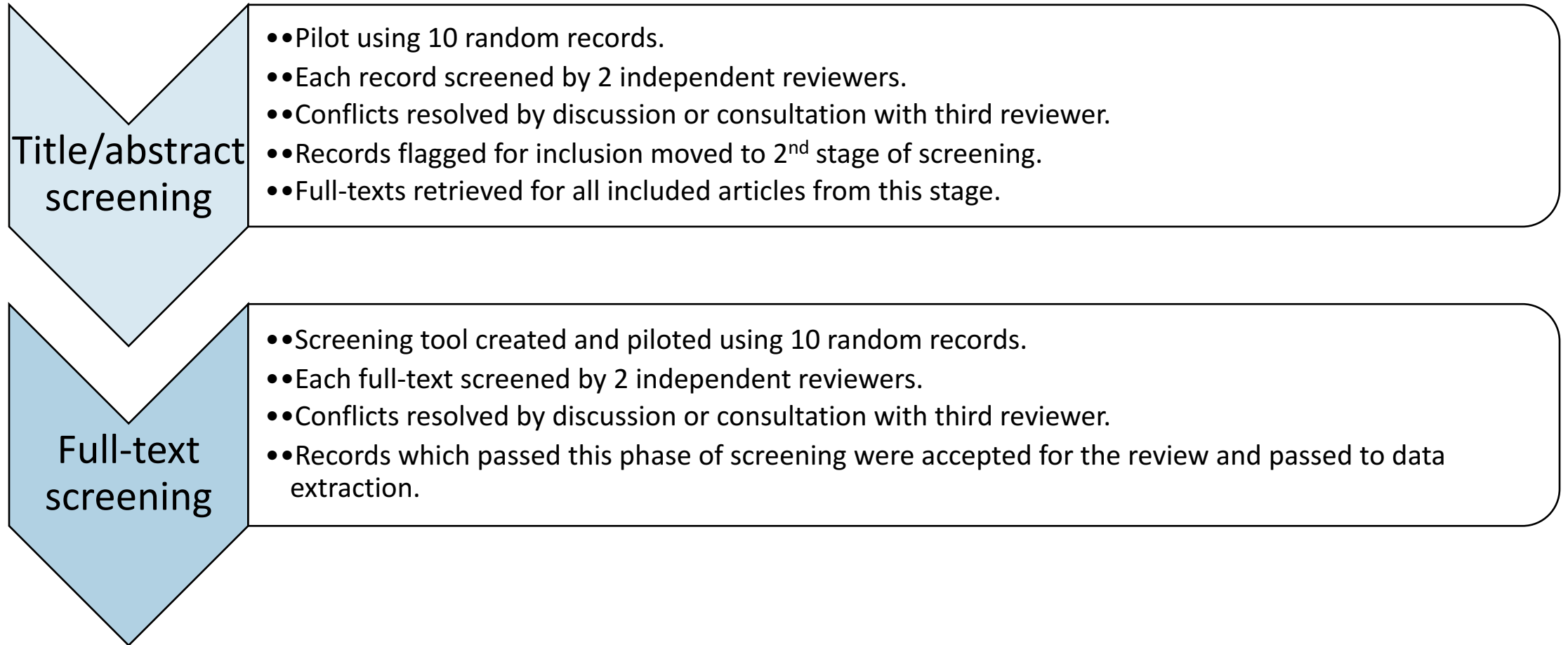- •Pubmed
- •Scopus

Supplementary Sources/ Strategies

- •Reference lists of all included articles
- •Hand searches of key journal: Age and Aging, Journals of Gerontology Series B, Journal of the American Geriatrics Society, The Gerontologist.

Electronic Databases

- •CINAHL Complete
- •ASSIA
- •Pubmed
- •Scopus
- •Web of Science
- •PsycINFO

Methods: Screening Stage 1 + 2

Title/abstract screening

- •Pilot using 10 random records.
- •Each record screened by 2 independent reviewers.
- •Conflicts resolved by discussion or consultation with third reviewer.
- •Records flagged for inclusion moved to 2nd stage of screening.
- •Full-texts retrieved for all included articles from this stage.

Full-text screening

- •Screening tool created and piloted using 10 random records.
- •Each full-text screened by 2 independent reviewers.
- •Conflicts resolved by discussion or consultation with third reviewer.
- •Records which passed this phase of screening were accepted for the review and passed to data extraction.

Search and Study Selection

Records identified through database searching
CINAHL (n=48)
ASSIA (n=322)
PsycINFO (n=240)
Pubmed (n=46)
Scopus (n=98)
Web of Science (n=53)

Additional records identified through hand searching of key journals
(n=0)

Non-duplicate Citations Screened
(n= 704)

Inclusion/Exclusion Criteria Applied to Title/Abstract Review

Records excluded
(n=638)

Full-text articles assessed for eligibility
(n=66)

Full Text Excluded (n = 350)
- *Non-human study (n=0)*
- *Ineligible publication date (n=64)*
- *Outside geographic context (n=1)*
- *Irrelevant population (n=60)*
- *Ineligible publication method (n=177)*
- *Does not reference care access/navigation barriers/facilitators (n= 43)*
- *Full text unavailable (n=3)*
- *Not published in English (n=2)*

Articles reviewed from reference lists
(n=290)

Articles included
(n= 6)

Methods: Data Extraction

Process

- Data extraction performed by lead author (LK)

- Extraction form (excel) drafted in consideration of the JBI Manual for Evidence Synthesis[10] and reviewed by research team.
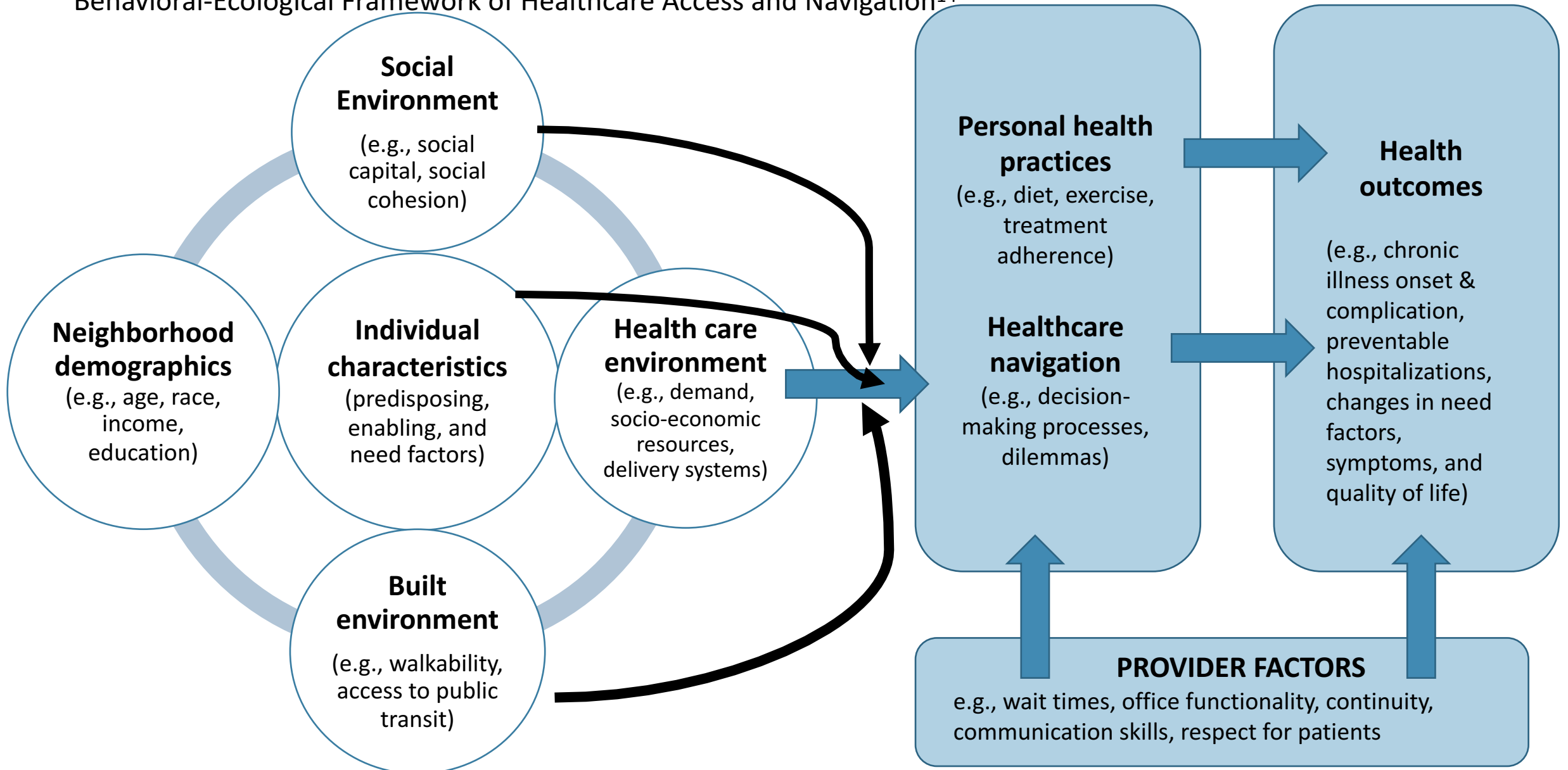
Data Extraction Categories

- Article details (authors, year, journal, country, continent)

- Setting

- Method

- Objective

- Sample Details and Demographics (age range, ethnicity/cultural status, gender, living arrangements).

- Barriers to care access/navigation*

- Facilitators of care access/system navigation*

*Framed using Behavioral-Ecological Framework of Healthcare Access and Navigation[14]

Next Steps: A Structured Synthesis
Behavioral-Ecological Framework of Healthcare Access and Navigation[14]

Social Environment
(e.g., social capital, social cohesion)

Neighborhood demographics
(e.g., age, race, income, education)

Individual characteristics
(predisposing, enabling, and need factors)

Health care environment
(e.g., demand, socio-economic resources, delivery systems)

Built environment
(e.g., walkability, access to public transit)

Personal health practices
(e.g., diet, exercise, treatment adherence)

Healthcare navigation
(e.g., decision-making processes, dilemmas)

Health outcomes
(e.g., chronic illness onset & complication, preventable hospitalizations, changes in need factors, symptoms, and quality of life)

PROVIDER FACTORS
e.g., wait times, office functionality, continuity, communication skills, respect for patients

Results

Author (Year)	Location	Study Design	Objective	Sample
Machielse (2015)	The Netherlands EUR	Qualitative interviews, analysis of social work logbooks	To arrive at a 'social isolation typology' to offer insight into the heterogeneity of socially isolated older adults that may help social workers in providing suitable interventions for specific clients.	Socially isolated older adults (n=43) age 55-94, all living alone without social supportive relationships (practical, emotional, companionship) and the social workers supporting them (n=16).
Machielse (2020)	The Netherlands EUR	Qualitative interviews	To investigate the needs and subjective experiences of older adults who have been isolated for a long time and have problems in multiple life domains.	Severely socially isolated older adults (n=25), age 60+, absence of social contacts with family/friends, absence of supportive relationships for 5+ years, problems in multiple life domains.
Montayre et al. (2020)	New Zealand OC	Qualitative interviews	To explore the views of older adults on the use of the terminology 'elder orphans' and the implication of using the terminology in health and social care systems.	Community-dwelling older adults (n=11) age 67-87, living independently and lacking a close family member/designate surrogate/caregiver in NZ.
Portacolone (2013)	United States NA	Ethnography	To capture the experience of the condition of living alone in the United States.	Solo-dwelling older adults (n=47) age 75+, never married, widowed, divorced, or married to a spouse who was institutionalized.
Portacolone (2015)	United States NA	Ethnography	To assess the values, preferences, and concerns of a diverse sample of older Americans living alone.	Older San Fransicans living alone (n=47) age 75+, without a cohabitant in a non-institutional setting.
Thaggard & Montayre (2019)	New Zealand OC	Qualitative interviews	To explore the experiences of 'elder orphans' living independently in the community on their own without immediate close family support regarding health and social care issues.	Community-dwelling older adults (n=11), age 67-87, living independently and lacking a close family member/designate surrogate or caregiver in NZ.

Preliminary Comments

- No relevant Canadian literature was identified.

- All studies identified used qualitative approaches.

- A lack of conceptual clarity is problematic in synthesis of available knowledge.

- A focus on 'lived experience' rather than explicit exploration of issues in care access and navigation.

- Supplementary review of grey literature may be warranted.

- **Questions?**

References

1.   Schulz R, Eden J. *Families caring for an aging America*. Washington, DC: The National Academies Press, 2016.

2.   Phillipson C. *Ageing*. Cambridge, UK: Polity Press, 2013.

3.   Redfoot D, Feinberg L, Houser AN. *The aging of the baby boom and the growing care gap: a look at future declines in the availability of family caregivers*. Washington, DC: AARP Public Policy Inst, 2013.

4.   Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. Gerontologist 2015;**55**:309–19.doi:10.1093/geront/gnu177

5.   Carney MT, Fujiwara J, Emmert BE, *et al*. Elder orphans hiding in plain sight: a growing vulnerable population. Curr Gerontol Geriatr Res 2016;**2016**:1–11.doi:10.1155/2016/4723250

6.   Farrell TW, Widera E, Rosenberg L, Rubin CD, Naik AD, Braun U, Torke A, Li I, Vitale C, Shega J; Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society. AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults. J Am Geriatr Soc. 2017 Jan;65(1):14-15. doi: 10.1111/jgs.14586.

7.   Munn Z, Peters MDJ, Stern C, *et al*. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Med Res Methodol 2018;**18**:143. doi:10.1186/s12874-018-0611-x

8.   Tricco AC, Lillie E, Zarin W, *et al*. A scoping review on the conduct and reporting of scoping reviews. BMC Med Res Methodol 2016;**16**:15. doi:10.1186/s12874-016-0116-4

9.   Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005;**8**:19–32.doi:10.1080/1364557032000119616

10.   Peters MDJ, Godfrey C, McInerney P. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z, eds. *JBI manual for evidence synthesis*, 2020.doi:10.46658/JBIMES-20-12

11.   Kunerth J. Seniors Outliving family, becoming elder orphans, Chicago Tribune 2003.

12.   Sherer R. Who will care for elder orphans. Geriatric Times 2004.

13.   Varner J. The elder orphans: who are they? Ala Nurse 2005;**32**:19–21.

14.   Ryvicker M. A Conceptual Framework for Examining Healthcare Access and Navigation: A Behavioral-Ecological Perspective. Soc Theory Health. 2018 Aug;16(3):224-240. doi: 10.1057/s41285-017-0053-2.