

# Scoping the experience of terminal illness in working-age people

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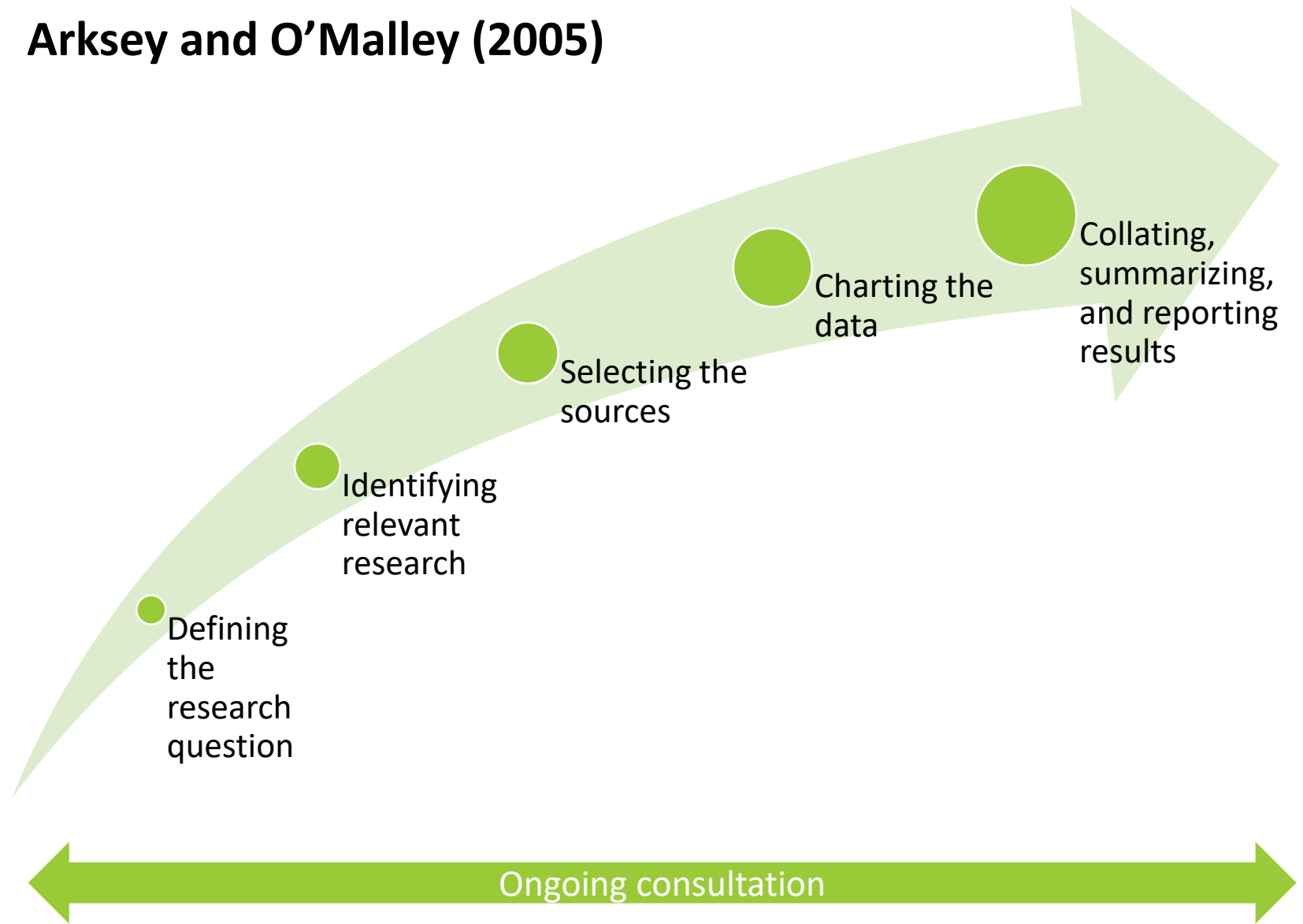


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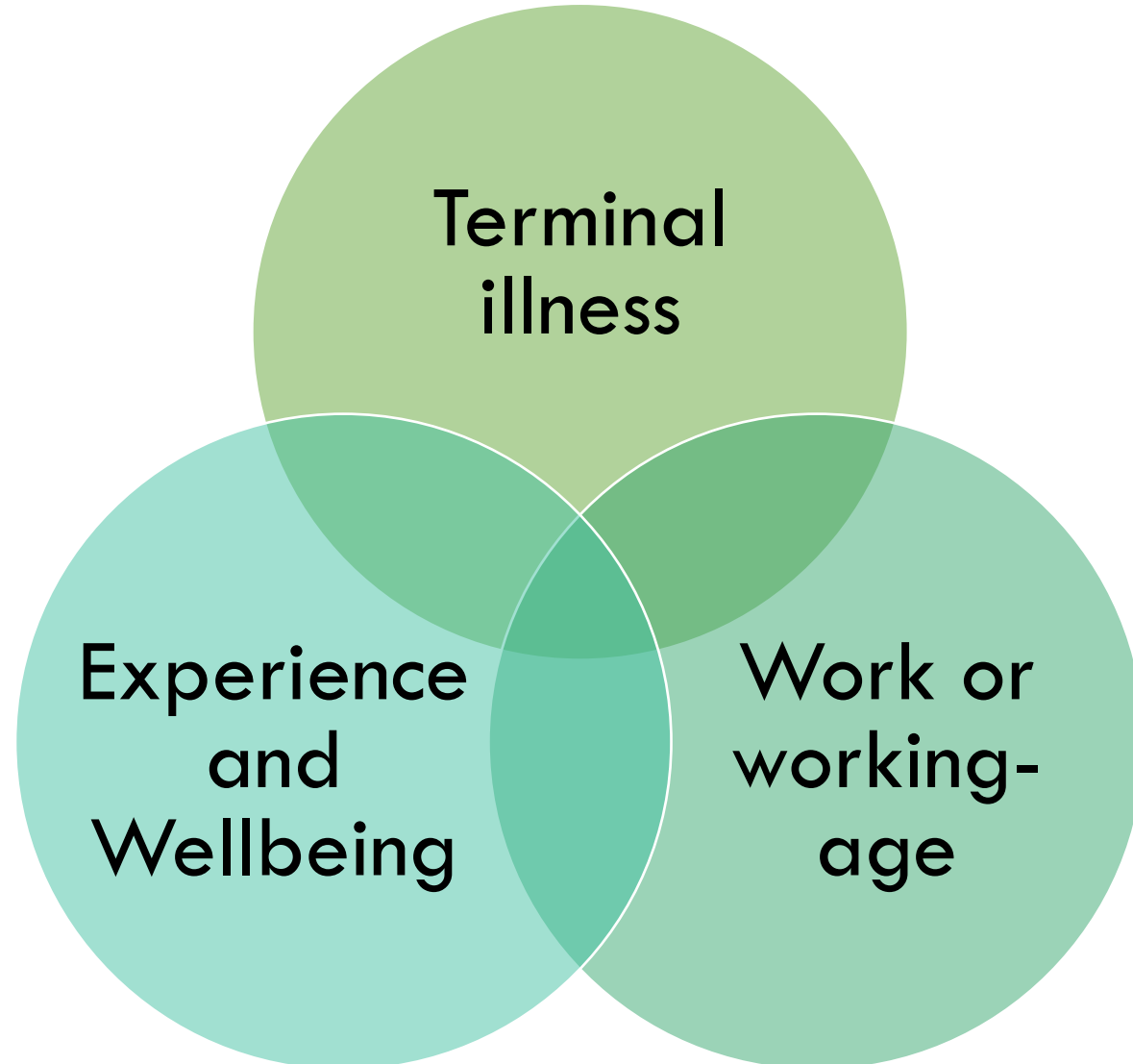
## Arksey and O'Malley (2005)

# Scoping review methodology



# The research question

**What is known from the existing literature about the experiences of terminally ill people of working-age ?**



## Selecting the sources

**2,952** articles identified



**2,313** abstracts and titles screened



**18** articles eligible for full screening



**6** articles eligible for inclusion



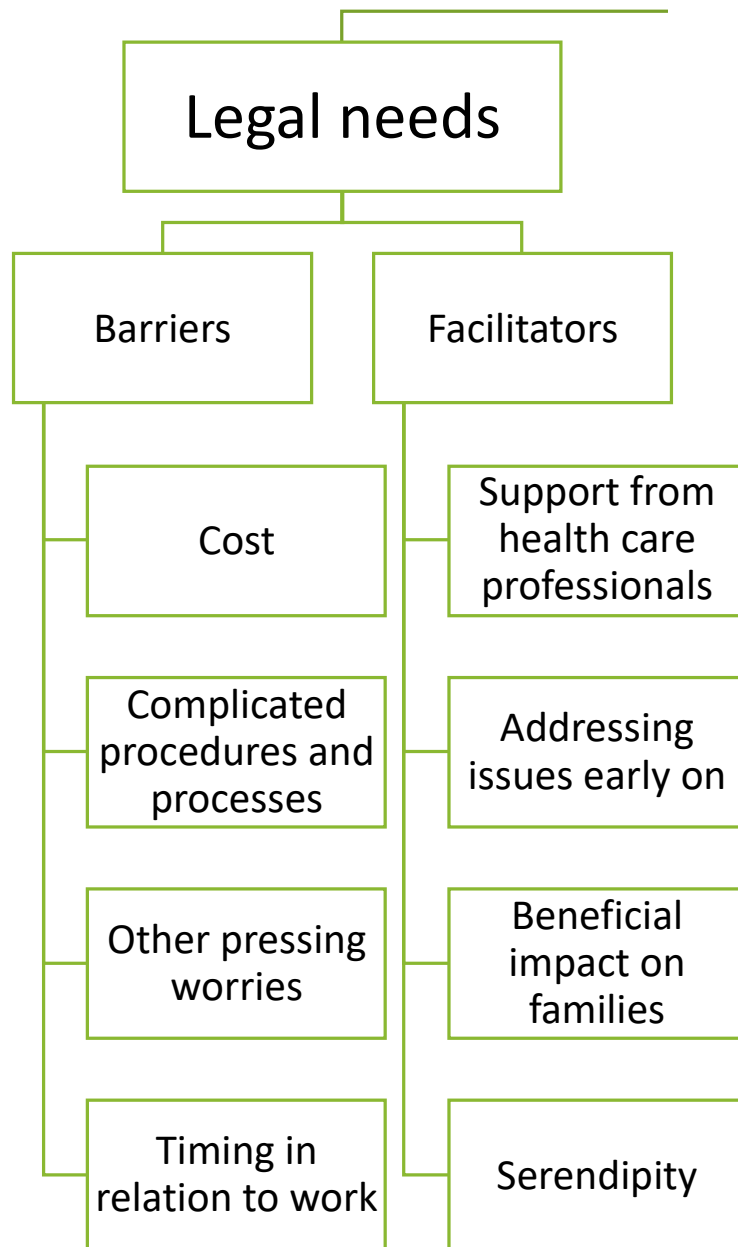
# Study characteristics

| Author (year)                | Title   | Country & sample size            | Study design (analysis)   | Age                                      |
|------------------------------|---|----------------------------------|---|--|
| <b>Emanuel et al. (2010)</b> | Economic impact of terminal illness and the willingness to change it  | n=11, Kerala, India              | Open-ended questions (content analysis)                               | Range: 32-57 years                       |
| <b>Cagel et al. (2015)</b>   | Financial burden among US households affected by cancer at the end of life  | n=176, USA                       | Telephone interview (Quantitative)                                    | Mean age 55.9<br>SD=17.8                 |
| <b>Westaby et al. (2005)</b> | Intentions to work during terminal illness: an exploratory study of antecedent conditions   | n=125, USA                       | Survey (Quantitative)   | Mean: 57.8 years                         |
| <b>Essue et al. (2013)</b>   | Living with economic hardship at the end of life  | n=30, Australia                  | Structured and semi-structured Interviews (thematic content analysis) | Mean age 68 years (+/-10 years)          |
| <b>Oechsle et al. (2009)</b> | Physical activity, quality of life, and the interest in physical exercise programs in patients undergoing palliative chemotherapy | n=53, Germany                    | Questionnaire survey (quantitative)                                   | Median: 58 years<br>Range: 29-76 years   |
| <b>Close et al. (2021)</b>   | Qualitative investigation of patient and carer experiences of everyday legal needs towards end of life.                           | n=14, UK (mixed urban and rural) | Semi-structured interviews (thematic analysis)                        | Mean age 70.3 years<br>Range: 38-87years |



# 4. Main themes





*“So you know the frustration is massive when you don’t know what to ask for... it’s not just the information, it’s also where to ask, who do you contact when you settle on those things that are available, how do you make those connections about what you need, how do you write the right letter and also trying to get help and how do you get follow-up?” Close et al (2020)*

*“[The specialist palliative care nurse] said “You’ll have your mobility sticker for the car?” and I said “They knocked us back” and she says “You what? It will be through the door within two days” and it was.” Close et al (2020)*



*"I can't work full time [anymore]. My wife has given up her job to look after me. Now we're living on our savings and it's hard... My operation will cost \$1000...my business is virtually non-existent. So we have living costs, and have to eat and pay our bills but have nothing coming in" Essue et al (2013)*

**Financial strain was common, especially when the patient was**

- **Male**
- **Ethnic minority**
- **No health insurance**

**Emmanuel et al (2010); Cagel et al (2015)**

## Financial stress

Stopping work

Cost of care and insurance

Use of savings

Impact on caregiver

Unaware of support available





# Mental health

Depression

Anxiety

Sleep disturbance

*“I need to apply for the sickness allowance but I haven’t done so yet as I am very overwhelmed by the number of forms and amount to read. I’m mentally very tired and want to stay away from stress”  
Essue et al (2012)*

*“Because at the time ... I was worried about everything and I was starting to get upset and anxious about it all. It is just you don’t know what you are eligible for. How are you meant to know? Making sense of the information ... and how it relates to you is virtually impossible.” Close et al (2021)*



# Discussion: Main findings

- Direct result of terminal illness patients experience significant financial and legal challenges in addition to the challenges of their diagnosis
- These challenges can:
  - compound mental health and wellbeing
  - adversely affect family and next of kin
  - vary depending on individual characteristics, and illness severity
- There is very limited evidence about the experience of terminal ill among those of working-age
  - Few studies available
  - Lack of focus on wellbeing



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