Risk for Adverse Outcomes related to Community Caregiver Stress

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Stressful times......
The proportion of older adults, including community dwellers, is increasing worldwide. This has resulted in increased numbers of older adults labeled as “frail”. Older adults are at increased risk of adverse healthcare outcomes. Prognostication is important to personalise care for older adults. What role do caregivers and caregiver stress play in this?
COLLaboration on AGEing-COLLAGE: Ireland's three star reference site for the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA)


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Related Articles
Factors associated with successful aging in persons aged 65 to 75 years
European Geriatric Medicine, Vol. 5, Issue 6

Ageing and fasting glucose values – the role of cardiovascular events
IRELAND
Site: Ireland: Collaboration on Ageing (COLLAGE)

COLLAGE is a collaboration formed by Cork Healthy Ageing (through Resource Generation & Education - University College Cork) and Louth Age Friendly County. This cross-sectoral initiative includes healthcare providers, local authorities, older people economic development agencies, SMEs, industry partners, community groups and academia.

The CARTS (Community Assessment of Risk and Treatment Strategies) Programme aims to delay or prevent functional decline and frailty and 3 adverse outcomes: institutionalisation, hospitalisation and death. It is an integrated screening assessment and treatment package that uses a rapid screening tool (providing a global assessment in 2-5 minutes) helping identifying and understanding the risk factors and thus to define the most beneficial interventions for the patients.

Within the framework of Ireland’s National Age-Friendly Counties Programme, Louth has set out as the first county in Ireland to develop and implement an age-friendly county action plan: the Louth Age-Friendly County Initiative (LAFCI). Among its objectives there are an improvement in the seniors’ health and well-being, an increased participation of older people in the community life and the delivery of services through imaginative and cost-effective partnerships. Housing, building and transport are among the “physical” environments that are object of innovation in order to increase their age-friendliness.

The Let Me Decide* Advance Care Planning and Palliative Care Programme in Long-term Care implements an advance care planning programme and a palliative care educational initiative into long-term care settings. The objective is to increase older people’s independency and reduce unnecessary treatments.

Some examples of the impact of these good practices:

- CARTS is improving patients’ empowerment, allowing them to take part in the definition of their specific management plans, based on their personal risk level. 803 patients were tested in the pilot phase, currently 5000 older adults are being assessed.

- Preliminary data on the use of CARTS show that high-risk individuals are 33% more likely to be institutionalised, 3 times more likely to be hospitalised and 16 times more likely to die than the low-risk group within 6 months from the assessment. The tool proved to have a superior sensitivity, accuracy and specificity in predicting long term care, hospitalisation and death, improving care delivery, detection of frailty, communication and integration of care settings.

- 13,500 citizens aged 65+ participated in the pilot of the Louth Age-friendly Initiative. The guidelines for "Place to Flourish", directed to improving the person-centred characteristics of the environment in long term care setting, were adopted in 181 out of 581 places in residential care.

For further information: https://www.collage-ireland.eu/
Increasing recognition of the role caregivers play in the care of older people.

EIP on AHA composed of 6 Action Groups including a group dedicated to the prevention of frailty and functional decline.

Caregiver action area of the Action Group A3, coordinated by UCC (Prof William Molloy) and NUIG (Dr Rónán O’Caoimh).

This group focuses on improving the quality of life of older adults through identification, assessment and management of the needs of caregivers.
A3 Action Group on Prevention and Early Diagnosis of Frailty and Functional Decline, Both Physical and Cognitive, in Older People

Figure 1. Governance Structure of the Action Group A3
EIP on AHA
Distribution of deliverables/ Action Area

1 - Frailty in General
2 - Functional Decline
3 - Cognitive Decline
4 - Nutrition
5 - Care Givers & Dependency
6 - Physical Activity
EIP on AHA
Distribution of Commitments/Action Area

Commitments/Action Area

- Nutrition: 69
- Functional decline: 47
- Cognitive decline: 28
- Frailty in general: 27
- Physical activity: 21
- Caregivers: 7

Legend:
Healthcare in our community

Public Health Nurses in the Community c 1906
Healthcare in Ireland

- Small country... 4.5 million citizens. (Ref CSO 2011)
- 535,393 aged over 65, 11% of the population (70% increase from 1961).
- By 2041.......22% (1.4 million).
- 24,253 beds in Long-term care, costing 0.9% of GDP....equivalent to $2 billion (2011).
- 44,000 with dementia but by 2050 there will be 90,000-120,000 cases.
- Approx 10% >65 have mild cognitive impairment.
- In 2009 187,000 are carers in Ireland.
- 13% of caregivers are aged > 65 years.
- Average age of caregivers for older people is 73 years.
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- Average age of caregivers for older people is 73 years.
A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities

Jennifer L. Wolff, PhD; Brenda C. Spillman, PhD; Vicki A. Freedman, PhD; Judith D. Kasper, PhD

[+] Author Affiliations


ABSTRACT

Importance Family and unpaid caregivers commonly help older adults who are at high risk for poorly coordinated care.
Caregiving for older adults in the 21st century

- A total of 1,739 family and unpaid caregivers of 1,171 community-dwelling older adults with disabilities who participated in the 2011 US National Health and Aging Trends Study and National Study of Caregiving.
- Sample of caregivers providing substantial, some, or no help with health care, defined by coordinating care and managing medications.
- Results were extrapolated to total USA population.
- Examined:
  1. Caregiving-related effects, including emotional, physical & financial.
  2. Participation restrictions in valued activities,
  3. Work productivity loss.
Caregiving for older adults in the 21st century

- **Estimate:**
  - 14.7 million caregivers assisting 7.7 million older adults in USA.
  - 6.5 million (44.1%) provided substantial help, 4.4 million (29.8%) provided some help with health care.
# Caregiving for older adults in the 21st century

<table>
<thead>
<tr>
<th>Nature of Assistance Provided</th>
<th>Percentage</th>
<th>Factors</th>
<th>p-value 1</th>
<th>Factors</th>
<th>p-value 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability-related activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td>96.3</td>
<td>89.3</td>
<td>&lt;.001</td>
<td>82.3</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Transportation</td>
<td>92.4</td>
<td>86.2</td>
<td>&lt;.001</td>
<td>80.4</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Housework</td>
<td>95.6</td>
<td>82.0</td>
<td>&lt;.001</td>
<td>72.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Mobility</td>
<td>80.6</td>
<td>69.0</td>
<td>&lt;.001</td>
<td>60.6</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Banking</td>
<td>78.1</td>
<td>55.7</td>
<td>&lt;.001</td>
<td>30.2</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Self-care</td>
<td>70.4</td>
<td>43.0</td>
<td>&lt;.001</td>
<td>31.2</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Health system logistics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make appointments</td>
<td>90.8</td>
<td>53.1</td>
<td>&lt;.001</td>
<td>14.8</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Order medicines</td>
<td>83.6</td>
<td>36.7</td>
<td>&lt;.001</td>
<td>16.6</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Handle insurance issues</td>
<td>38.0</td>
<td>21.5</td>
<td>&lt;.001</td>
<td>7.3</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Health management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td>45.1</td>
<td>24.1</td>
<td>&lt;.001</td>
<td>15.2</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Foot care</td>
<td>44.1</td>
<td>23.9</td>
<td>&lt;.001</td>
<td>14.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Skin care</td>
<td>38.8</td>
<td>23.1</td>
<td>&lt;.001</td>
<td>7.9</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Exercise</td>
<td>33.0</td>
<td>19.6</td>
<td>&lt;.001</td>
<td>10.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Dental care</td>
<td>28.2</td>
<td>9.2</td>
<td>&lt;.001</td>
<td>3.6</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
Caregiving for older adults in the 21\textsuperscript{st} century

- Caregivers were more likely to be female and adult children.
- Caregivers providing substantial help with healthcare activities were older than caregivers who provided no healthcare!
- They were also less likely to rate their health as excellent or very good.
- Almost half (45.5\%) of the caregivers providing substantial help with health care assisted an older adult with dementia.
The use of supportive services was low but was greater among caregivers providing substantial vs some or no help (26.7% vs 15.5% & 7.6%, p<0.001).

Caregivers were significantly more likely to experience:
1. Emotional difficulty (aOR 1.79; 95%CI, 1.20-2.66),
2. Physical difficulty (aOR, 2.03; 95%CI, 1.39-2.97),
3. Financial difficulty (aOR, 2.21; 95%CI, 1.52-3.22).
Caregivers were 5 times as likely to experience participation restrictions in valued activities (aOR, 5.32; 95% CI, 3.31-8.59).

More than 3 times as likely to experience work productivity loss (aOR, 3.14; 95% CI, 1.40-7.02).

Q.....What effect does this have on older patients?
The Challenge of Managing Frail Older Adults in the Community

Who is at risk?

It is possible to identify risk but how do we quantify it?

What is the greatest risk?

Should this person stay at home.....go to a nursing home?

What is the most appropriate response?
Successful prevention of functional decline requires more knowledge about risk factors and the stratification of patients is key.

Risk is the chance an event will occur in the future.

Amount of (likelihood) potential harm multiplied by the magnitude of that harm.

It is possible to identify risk but how do we quantify it?

Can the effects of caregiver stress be used to predict patients who will have worse healthcare outcomes?

Are there instruments available for healthcare workers to use in the community?
Review

Risk prediction in the community: A systematic review of case-finding instruments that predict adverse healthcare outcomes in community-dwelling older adults

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\textsuperscript{b} COLlAGE (COLlaboration on AGEing), University College Cork, Cork City and Louth Age Friendly County Initiative, Co Louth, Ireland
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\textsuperscript{d} Institute for Research Primary Healthcare, Jordi Gol University, Barcelona, Spain
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\textbf{Article info}

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Received 22 February 2015

\textbf{Abstract}

Few case-finding instruments are available to community healthcare professionals. This review aims to identify short, valid instruments that detect older community-dwellers risk of four adverse outcomes:
Review of community based risk prediction instruments

4,479 citations

4,428 abstracts excluded

451 papers independently reviewed

405 papers excluded

Full text of 46 papers included

23 unique instruments

Reasons for exclusion
- Frailty measures (n=51)
- Other measures (n=84)
  - Activities of Daily Living (n=13)
  - Cognition including delirium (n=5)
  - Comorbidity (n=5)
  - Falls (n=1)
  - Mood (n=1)
  - Multiple other measures (n=9)
  - Nutrition (n=15)
  - Physical function (n=19)
  - Polypharmacy (n=3)
  - Self-rated including quality of life (n=13)
- Pertaining to trial interventions (n=91)
- Complex algorithms (n=3)
- Not in a community setting (n=34)
- Predictors but no measures (n=62)
- Commentary/update paper/protocol (n=8)
- Not in English language (n=1)
- Others (n=32)
Receiver Operating Characteristics (ROC) curves

![ROC Curves Diagram](image)

- Sensitivity = True positive rate
- (1-specificity) = False Positive Rate

Legend:
- Blue line: Worthless
- Purple line: Good
- Yellow line: Excellent
Predictive accuracy varied between instruments.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Area under the curve</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalisation</td>
<td>0.60-0.73</td>
</tr>
<tr>
<td>Institutionalisation</td>
<td>0.70-0.74</td>
</tr>
<tr>
<td>Functional decline</td>
<td>0.63-0.78</td>
</tr>
<tr>
<td>Death</td>
<td>0.56-0.82</td>
</tr>
</tbody>
</table>
Review of community based risk prediction instruments

- Few instruments identified in this systematic review, most were of poor quality.
- Half were validated by retrospective analysis of data from patients enrolled in existing longitudinal studies.
- Many potentially useful instruments were excluded as they are not validated in community settings.
- Reflecting other systematic reviews: instruments predicting hospitalisation had poor accuracy.
- Few instruments measured risk of institutionalisation.
- Few instruments included any kind of measure of caregiver stress.
Aim: To screen for frailty & risk of adverse healthcare outcomes by taking the role of caregivers into account.
Risk Factors for Adverse Outcomes in Community Dwellers

- Presence of risk factors
- Reduced resilience
- Frailty

Age (>75 years)
- No formal education
- Living alone
- Chronic medical conditions
- Depression
- Cognitive impairment
- Sensory impairment (visual or hearing)
- Poor nutrition
- Poor mobility and ADL dependence

Caregiver stress
What does being frail mean in practice?

Fig 1. Frail older people display low resilience to minor stressors (e.g. urinary tract infection). This figure adapted from Clegg A, Young J, Iliffe S, et al. Frailty in elderly people. Lancet 2013;381:753(Figure 1) with permission from Elsevier.
The Risk Instrument for Screening in the Community (RISC)

- Assesses risk of adverse outcomes within a defined time period (i.e. one year).
- Measures **care needs** (mental state, medical state and ADLs) & **care deficits** (ability of the caregiver network to manage any issues).
- Quick, objective and reproducible
- Predicts hospitalisation, institutionalisation and death
  - Triage those at higher risk to rapid assessment
- Enhances the integrated care agenda
  - A common language between primary and secondary care
Screening for markers of frailty and perceived risk of adverse outcomes using the Risk Instrument for Screening in the Community (RISC)

Rónán O’Caoimh1,2, Yang Gao1, Anton Svendrovski2, Elizabeth Healy3, Elizabeth O’Connell4, Gabrielle O’Keeffe5, Una Cronin1, Eileen O’Herlihy1, Nicola Cornally1,6 and William D Molloy1,7

Abstract

Background: Functional decline and frailty are common in community dwelling older adults, increasing the risk of adverse outcomes. Given this, we investigated the prevalence of frailty-associated risk factors and their distribution according to the severity of perceived risk in a cohort of community dwelling older adults, using the Risk Instrument for Screening in the Community (RISC).

Methods: A cohort of 803 community dwelling older adults were scored for frailty by their public health nurse (PHN) using the Clinical Frailty Scale (CFS) and for risk of three adverse outcomes: i) institutionalisation, ii) hospitalisation and iii) death, within the next year, from one (lowest) to five (highest) using the RISC. Prior to scoring, PHNs stated whether they regarded patients as frail.

Results: The median age of patients was 80 years (interquartile range 10), of whom 64% were female and 47.4%
## Risk Matrix

<table>
<thead>
<tr>
<th></th>
<th>Minimal</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Certain</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Extreme Risk</td>
</tr>
<tr>
<td><strong>Likely</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>High Risk</td>
</tr>
<tr>
<td><strong>Possible</strong></td>
<td></td>
<td></td>
<td>Medium Risk</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Unlikely</strong></td>
<td></td>
<td>Low Risk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Rare</strong></td>
<td>Minimal Risk</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The RISC records the presence of Concerns, the Severity of concerns (mild, moderate, and severe) and each Caregivers’ Network’s ability to manage these concerns.

Across three domains: mental state, activities of daily living and medical state.

Risk = Concern + Status (of the Concern) – Caregiver Network

→ Provided the Care Network is unchanged and with consideration for the expected course of the patient.
Caregiver Network Score

- Measured as a 5 point Likert scale:
  1. Minimal/rare
  2. Low/unlikely
  3. Moderate/possible
  4. High/likely
  5. Extreme/certain

- Validation conducted among community dwellers Cork 2012-2014.
Figure 2 Distribution of clinical frailty scale scores in the study population (n = 784).
Clinical Frailty Scale*

1. Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2. Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3. Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4. Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”, and/or being tired during the day.

5. Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6. Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7. Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8. Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. Terminally Ill – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In severe dementia, they cannot do personal care without help.


© 2007-2009. Version 1.2. All rights reserved. Geriatric Medicine Research, Dalhousie University, Halifax, Canada. Permission granted to copy for personal and educational purposes only.
Clinical Frailty Scale*

1. **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest.  
   \[N=6 (0.8\%)]

2. **Well** – People who have no active disease symptoms but are less fit than category 1. Often they exercise or are very active occasionally.  
   \[N=37 (4.7\%)]

3. **Managing Well** – People whose medical problems are well controlled, but are not regularly active beyond routine walking.  
   \[N=144 (18.4\%)]

4. **Vulnerable** – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”, and/or being tired during the day.  
   \[N=171 (21.8\%)]

5. **Mildly Frail** – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone meal preparation and housework.  
   \[N=138 (17.6\%)]

6. **Moderately Frail** – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (sitting standby) with dressing.  
   \[N=221 (28.2\%)]

7. **Severely Frail** – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~2 years).  
   \[N=49 (6.3\%)]

8. **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.  
   \[N=13 (1.7\%)]

9. **Terminally Ill** – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.  
   \[N=5 (0.6\%)]

**Scoring frailty in people with dementia**

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal. In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting. In severe dementia, they cannot do personal care without help.

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## RISC Score Sheet

### Demographics

**Personal Details:**
Name __________________________

Address ________________________________________________________________

Gender:  
M  []  F  []  DOB / /  ID ____________________

**Living Arrangements:**
- Alone  []  Spouse  []  Child  []  Other ____________________

### Instructions

If NO concern for a Domain, move on to the next Domain. Complete all 4 domains.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concern</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is there concern about issues in this domain? (Circle Yes or No)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Then complete Step 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Circle the present severity of the concern (Circle: 1, 2, 3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Mild.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Moderate.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Severe.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Then complete Step 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the caregiver network able to manage (Circle: 1, 2, 3, 4 or 5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Can manage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Caner strain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Some gaps</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Cannot manage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Abcent/ability</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Global Risk Score

(circle 1, 2, 3, 4 or 5)

#### A. Institutionalisation
Overall risk of admission to long-term care (nursing home) in the next year.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal / rare</td>
<td>Low / unlikely</td>
<td>Moderate / possible</td>
<td>High / likely</td>
<td>Extreme / certain</td>
</tr>
</tbody>
</table>

#### B. Hospitalisation
Risk of hospitalisation including prolonged admission or readmission in the next year.

<table>
<thead>
<tr>
<th>1</th>
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</tr>
</tbody>
</table>

#### C. Death
Risk of death in the next year.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
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### Global Risk Score Definitions

1. **Minimal**: Little or no serious consequence related to the risk / Rare: The event will almost never occur.
2. **Low**: Small impact from the risk, unlikely to cause serious harm / Unlikely: Low probability of the event occurring.
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4. **High**: Serious impact likely from the risk / Likely: High probability of the event occurring.
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# RISC Score Sheet®

## Demographics

<table>
<thead>
<tr>
<th>Personal Details:</th>
<th>Name ____________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td>__________________________________</td>
</tr>
<tr>
<td>Gender: M ☐ F ☐</td>
<td>DOB / / ID ______________________</td>
</tr>
</tbody>
</table>

## Living Arrangements:
- Alone ☐  Spouse ☐  Child ☐  Other _________

## Instructions
- If NO concern for a Domain, move on to the next Domain. Complete all 4 domains.

## Step 1

### Domain
- Mental State
- ADLs
- Medical/Physical State
- Other specify__________

### Concern
- N ☐ Y ☐

### Step 2

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
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<th>4</th>
<th>5</th>
</tr>
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<tr>
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## Step 3

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The Risk Instrument for Screening in the Community (RISC): a new instrument for predicting risk of adverse outcomes in community dwelling older adults

Rónán O’Caoimh1,7,a, Yang Gao1, Anton Svendrovski2, Elizabeth Healy3, Elizabeth O’Connell4, Gabrielle O’Keeffe5, Una Cronin1, Ester Igras1, Eileen O’Herlihy1, Carol Fitzgerald1, Elizabeth Weathers1,6, Patricia Leahy-Warren6, Nicola Cornally1,6 and D. William Molloy1,7

Abstract

Background: Predicting risk of adverse healthcare outcomes, among community dwelling older adults, is difficult. The Risk Instrument for Screening in the Community (RISC) is a short (2–5 min), global subjective assessment of risk created to identify patients’ 1-year risk of three outcomes: institutionalisation, hospitalisation and death.

Methods: We compared the accuracy and predictive ability of the RISC, scored by Public Health Nurses (PHN), to the Clinical Frailty Scale (CFS) in a prospective cohort study of community dwelling older adults (n = 803), in two Irish PHN sectors. The area under the curve (AUC), from receiver operating characteristic curves and binary logistic regression models, with odds ratios (OR), compared the discriminatory characteristics of the RISC and CFS.
RISC Instrument Testing

Institutionalisation  
AUC = 0.70

Hospitalisation  
AUC = 0.61

Death  
AUC = 0.70

ROC curves comparing the outcomes between the RISC and Clinical Frailty Scale
RISC Instrument Testing

Kaplan meier survival analysis comparing high and low risk patients (classified by RISC)
MEASURING THE EFFECT OF CARERS ON PATIENTS’ RISK OF ADVERSE HEALTHCARE OUTCOMES USING THE CAREGIVER NETWORK SCORE

R. O’CAOIMH1,2,3, N. CORNALLY1,4, A. SVENDROVSKI3, E. WEATHERS1,4, C. FITZGERALD1, E. HEALY6, E. O’CONNELL7, G. O’KEEFFE8, E. O’HERLIHY1, Y. GAO1, R. O’DONNELL1, R. O’SULLIVAN1, P. LEAHY-WARREN4, F. ORFILA9, C. PAÚL10, R. CLARNETTE11, D.W. MOLLOY1,3

1. Centre for Gerontology and Rehabilitation, University College Cork, St Finbar’s Hospital, Douglas road, Cork City, Ireland; 2. Health Research Board Clinical Research Facility Galway, National University of Ireland, Galway, Geata an Eolais, University Road, Galway, Ireland; 3. COLLAGE (COllaboration on Ageing), University College Cork, Cork City and Louth Age Friendly County Initiative, Co Louth, Ireland; 4. School of Nursing & Midwifery, University College Cork, Ireland; 5. UZIK Consulting Inc., 86 Gerrard St E, Urtt 12D, Toronto, ON, M5B 2J1 Canada; 6. Centre for Public Health Nursing, Ballincollig and Bishopstown, Co Cork, Ireland; 7. Centre for Public Health Nursing, Mahon and Ballintemple, Cork City, Ireland; 8. Health Service Executive, South, Ireland; 9. Institute for Research Primary Healthcare, Jordi Gol University, Barcelona, Spain; 10. ICBAS, Institute of Biomedical Sciences Abel Salazar – University Of Porto, Porto, Portugal; 11. School of Medicine and Pharmacology, University of Western Australia, 35 Stirling Hwy, Crawley WA 6009, Australia.

Corresponding author: Dr Rónán O’Caoimh, Email: rocaoinmh@hotmail.com, Telephone: +353214901461, Facsimile: +3534901635

Abstract: Background: Although caregivers are important in the management of frail, community-dwelling older adults, the influence of different caregiver network types on the risk of adverse healthcare outcomes is unknown. Objective: To examine the association between caregiver type and the caregiver network subtest of The Risk Instrument for Screening in the Community (RISC), a five point Likert scale scored from one (“can manage”) to five (“absent/liability”). To measure the association between caregiver network scores and the one-year incidence of institutionalisation, hospitalisation and death. Design: Observational cohort study. Setting and Participants: Community-dwelling adults, aged >65, attending health centres in Ireland, n=779. Procedure and Measurements: The caregiver network subtest of the RISC was scored by public health nurses. Caregivers were grouped dichotomously into low-risk (score of one) or high-risk (scores two-five). Results: The majority of patients had a primary caregiver (582/779; 75%), most often their child (200/582; 34%). Caregiver network scores were higher, indicating greatest risk, when patients had no recognised primary caregiver and lowest when only a spouse or child was available. Despite this, patients with a caregiver were significantly more likely to be institutionalised than those where none was required or identified (11.5% versus 6.5%, p=0.047). The highest one-year incidence of adverse outcomes occurred when state provided care was the sole support; the lowest when private care was the sole support. Significantly more patients whose caregiver networks were scored high-risk required institutionalisation than low-risk networks; this association was strongest for managing medical domain issues, odds ratio (OR) 3.87:2.22-6.76. Only difficulty managing ADL was significantly associated with death, OR 1.72:1.06-2.79. There was no association between caregiver network score and risk of hospitalisation. Conclusion: This study operationalizes a simple method to evaluate caregiver networks. Networks consisting of close family (spouse/children) and those reflecting greater socioeconomic privilege (private supports) were associated with lower incidence of adverse outcomes. Caregiver network scores better predicted institutionalisation than hospitalisation or death.

Key words: Caregivers, social networks, frailty, risk assessment, community assessment.
Caregiver network scores were available for 779/801 (97%).

A primary caregiver was identified for 582/779 (74.7%) patients; 197/779 (25.3%) regarded as sufficiently independent to not have or require a carer.

1. Children (200/779, 26%) were the most common primary caregiver followed by:
2. Extended family (148/779, 19%),
3. Spouses (134/779, 17%),
4. Siblings or other distant family members, e.g. nephews, nieces and cousins (57/779, 7%).
The majority of patients (412/779, 53%) were living with someone. Of these....

1. 260/412 (63%) were living only with a spouse,
2. 70 (17%) only with a child and
3. 46 (11%) within an large extended family unit.

No differences in age, gender or percentage living alone between those with and without a recognised carer.
Table 1
Characteristics of caregiver network types where available (n=779)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Spouse</th>
<th>Child</th>
<th>Extended family unit</th>
<th>Sibling or other distant family</th>
<th>Others*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=134 (17.2%)</td>
<td>n=200 (25.7%)</td>
<td>n=148 (19.0%)</td>
<td>n=57 (7.3%)</td>
<td>n=43 (5.5%)</td>
</tr>
<tr>
<td>Age (y)</td>
<td>77.5±10</td>
<td>84±10</td>
<td>80±11</td>
<td>80±10</td>
<td>78±11</td>
</tr>
<tr>
<td>Female</td>
<td>46%</td>
<td>77%</td>
<td>69%</td>
<td>69%</td>
<td>53%</td>
</tr>
<tr>
<td>Living alone</td>
<td>2%</td>
<td>61%</td>
<td>47%</td>
<td>79%</td>
<td>82%</td>
</tr>
<tr>
<td>Cognitive Impairment</td>
<td>43%</td>
<td>32%</td>
<td>42%</td>
<td>20%</td>
<td>41%</td>
</tr>
<tr>
<td>AMTS score (y)</td>
<td>10±1</td>
<td>10±0</td>
<td>10±1</td>
<td>10±0</td>
<td>10±0</td>
</tr>
<tr>
<td>Barthel Index score (y)</td>
<td>17±7</td>
<td>17±6</td>
<td>16±7</td>
<td>18±5</td>
<td>18±5</td>
</tr>
<tr>
<td>Medications (n=335; 42%)</td>
<td>6±4</td>
<td>5±5</td>
<td>5±5</td>
<td>6±6</td>
<td>5±3</td>
</tr>
<tr>
<td>Receiving home help (y)</td>
<td>47%</td>
<td>65%</td>
<td>55%</td>
<td>52%</td>
<td>60%</td>
</tr>
<tr>
<td>Hospital length of stay (y)</td>
<td>0±0</td>
<td>0±0</td>
<td>0±0</td>
<td>0±0</td>
<td>0±0</td>
</tr>
<tr>
<td>Clinical Frailty Scale</td>
<td>6±2</td>
<td>5±2</td>
<td>5±2</td>
<td>4±3</td>
<td>5±3</td>
</tr>
<tr>
<td>PHN frailty perception (n=335; 42%)</td>
<td>57%</td>
<td>53%</td>
<td>47%</td>
<td>37%</td>
<td>35%</td>
</tr>
<tr>
<td>Charlson Index</td>
<td>1±2</td>
<td>1±2</td>
<td>1±2</td>
<td>1±2</td>
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</tr>
<tr>
<td>Institutionalisation (n=82; 10.2%)</td>
<td>13 (6.5%)</td>
<td>70 (11.5%)</td>
<td>25 (12.4%)</td>
<td>19 (12.7%)</td>
<td>10 (17.2%)</td>
</tr>
<tr>
<td>Hospitalisation (n=142; 17.7%)</td>
<td>35 (17.6%)</td>
<td>107 (17.8%)</td>
<td>30 (22.2%)</td>
<td>12 (20.7%)</td>
<td>19.0%</td>
</tr>
<tr>
<td>Death (n=125; 15.6%)</td>
<td>24 (12.1%)</td>
<td>101 (16.8%)</td>
<td>22 (16.3%)</td>
<td>29 (19.3%)</td>
<td>7 (12.1%)</td>
</tr>
</tbody>
</table>

Results are presented as n (percentage) or median ± interquartile range. PHN= Public health nurse; * Others includes patients receiving privately funded home supports, state funded home supports, care from friends and neighbours etc

Exploration of different caregiver subtypes: distribution of demographic details.
Table 1
Characteristics of caregiver network types where available (n=779)

<table>
<thead>
<tr>
<th>Variable</th>
<th>None (n=197, 25.3%)</th>
<th>Primary caregiver identified (n=582, 74.7%)</th>
<th>p</th>
<th>Child (n=200, 25.7%)</th>
<th>Sibling or other distant family (n=140, 18.9%)</th>
<th>Others* (n=57, 7.3%)</th>
<th>n=43 (5.5%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>79±10</td>
<td>81±10</td>
<td>0.06</td>
<td>77.5±9</td>
<td>84±10</td>
<td>80±10</td>
<td>78±11</td>
</tr>
<tr>
<td>Female</td>
<td>63%</td>
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<td>77%</td>
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</tr>
<tr>
<td>Living alone</td>
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<td>0.80</td>
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<td>79%</td>
</tr>
<tr>
<td>Cognitive Impairment</td>
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<td>37%</td>
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<td>32%</td>
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<td>20%</td>
</tr>
<tr>
<td>AMTS score</td>
<td>10±0</td>
<td>10±0</td>
<td>&lt;0.001</td>
<td>10±1</td>
<td>10±0</td>
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<td>Barthel Index score</td>
<td>20±2</td>
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</tr>
<tr>
<td>Medications</td>
<td>4±5</td>
<td>5±5</td>
<td>0.004</td>
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<td>5±5</td>
<td>5±3</td>
<td>5±4</td>
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<td>Receiving home help</td>
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</tr>
<tr>
<td>Receiving home help</td>
<td>38%</td>
<td>57%</td>
<td>&lt; 0.001</td>
<td>47%</td>
<td>65%</td>
<td>55%</td>
<td>52%</td>
<td>60%</td>
</tr>
<tr>
<td>Hospital length of stay</td>
<td>0±0</td>
<td>0±0</td>
<td>0.76</td>
<td>0±0</td>
<td>0±0</td>
<td>0±0</td>
<td>0±0</td>
<td>0±0</td>
</tr>
<tr>
<td>Clinical Frailty Scale</td>
<td>4±1</td>
<td>5±2</td>
<td>&lt; 0.001</td>
<td>6±2</td>
<td>5±2</td>
<td>5±2</td>
<td>4±3</td>
<td>5±3</td>
</tr>
<tr>
<td>PHN frailty perception (n=335; 42%)</td>
<td>19%</td>
<td>49%</td>
<td>&lt; 0.001</td>
<td>57%</td>
<td>53%</td>
<td>47%</td>
<td>37%</td>
<td>35%</td>
</tr>
<tr>
<td>Charlson Index</td>
<td>1±2</td>
<td>1±2</td>
<td>0.001</td>
<td>1±2</td>
<td>1±2</td>
<td>1±2</td>
<td>1±2</td>
<td>1±1.25</td>
</tr>
<tr>
<td>Hospitalisation (n=142; 17.7%)</td>
<td>13 (6.5%)</td>
<td>69 (11.5%)</td>
<td>0.95</td>
<td>7 (5.2%)</td>
<td>25 (12.4%)</td>
<td>19 (12.7%)</td>
<td>10 (17.2%)</td>
<td>(13.8%)</td>
</tr>
<tr>
<td>Death (n=125; 15.6%)</td>
<td>35 (17.6%)</td>
<td>107 (17.8%)</td>
<td>0.11</td>
<td>30 (22.2%)</td>
<td>32 (15.9%)</td>
<td>22 (14.7%)</td>
<td>12 (20.7%)</td>
<td>(19.0%)</td>
</tr>
</tbody>
</table>

Results are presented as n (percentage) or median ± interquartile range. PHN= Public health nurse; * Others includes patients receiving privately funded home supports, state funded home supports, care from friends and neighbours etc

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**Exploration of different caregiver subtypes: distribution of demographic details.**
Systematic Review and Meta-Analysis of the Impact of Carer Stress on Subsequent Institutionalisation of Community-Dwelling Older People

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Abstract

Background
In the caregiving literature there is a common assertion that a higher level of carer stress is a critical determinant of premature ending of homecare. However, this contention has not been systematically assessed. We therefore systematically reviewed and meta-analysed the prospective association between various forms of carer stress and subsequent institutionalisation of community-dwelling older people.

Methods
Systematic literature search of prospective studies measuring carer stress at baseline and institutionalisation at follow-up. Given substantial interchangeability in the measurement of carer stress, we included a wide number of exposure measures, namely: carer stress, burden, depression, distress, anxiety, burnout, and strain. Institutionalisation included both institutionalisation and care in the community.
## Caregiver Network Score

Table 3
Comparing odds ratios (95% Confidence intervals) between caregiver networks classified either as low-risk “can manage” (score 1/5) or high-risk “under strain/not managing” (scores 2-5/5), for the three domains of the RISC and each adverse outcome

<table>
<thead>
<tr>
<th>Domain</th>
<th>Institutionalisation</th>
<th>Hospitalisation</th>
<th>Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental state</td>
<td>1.35 (0.75 - 2.43)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td>1.59 (0.99 - 2.55)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical state</td>
<td>1.42 (0.82 - 2.44)</td>
<td>1.68 (0.97 - 2.91)</td>
<td></td>
</tr>
</tbody>
</table>

* p <0.05; Low-risk group = reference group
Ageing population is resulting in increasing numbers of older adults in the community.

Increased prevalence of frailty & risk of adverse healthcare outcomes.

Commensurate increase in the number of caregivers (usually unpaid & often experiencing caregiver stress & emotional, physical & financial consequences).

Exploring the impact of caregiver stress on patients risk of adverse healthcare outcomes in complex but important...“the missing piece”.

Few instruments available that use caregiver stress to predict adverse healthcare outcomes.

The RISC Caregiver Network score is a simple method for community healthcare providers to evaluate caregiver networks using a Likert scale from one to five.

Further study is required to examine the interplay between caregiver networks, adverse healthcare outcomes and caregiver stress to investigate if targeting and modifying these can reduce risk for community-dwelling older adults.
Thank You
Caring is wonderful....Questions?