Self-Neglect: Research to Practice
IASW Primary Care Special Interest Group Annual Conference
“Bridging the Gap”
12th September 2014
Dr. Mary Rose Day
Aim & Objectives

• Aim to increase knowledge on “Self-Neglect”

Objectives
• Define self-neglect
• Examine Theories & Conceptual Frameworks
• Data on prevalence of self-neglect
• Risk factors and indicators of self-neglect
• Assessment/mental capacity
• Assessment tools
• Self-Neglect: Case Studies
• Summarise and Conclude
Definitions of Self-Neglect

Self-Neglect can be described as an inability to meet one’s own basic needs.

“the inability or unwillingness to provide for oneself the goods and services needed to live safely and independently”

(Poythress et al. 2006, p. 7).

“the inability (intentional or non intentional) to maintain socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well being of the self-neglecters and perhaps even to their community”

(Gibbons et al. 2006 p. 16).
Diogenes Syndrome also known as *senile squalor syndrome*, *extreme self-neglect*, *domestic squalor*, *social withdrawal*, *apathy*, a tendency to *hoard rubbish (syllogomania)* and often lack of shame of their condition”

(Pavlou & Lach 2006, p.836).
Self-Neglect: Theories and Conceptual Frameworks

• No overarching explanatory model
• Self-neglect is socially constructed
• Complex interplay of association with physical, mental, social, personal and environmental factors
• Risk -vulnerability model (Paveza et al., 2008)
• Conceptual framework: elder self-neglect (ESN) Physical/Psycho-Social & Environmental Aspects of ESN (Iris et al., 2010)
Men
• 9.5% (65-74 years)
• 9.2% (75-84 years)
• and 10.1% (over 85 years).

Women
• 8.5% (65-74 years)
• 7.9% (75-84 years)
• and 7.5% (over 85 years).

Assessed 5 domains: hoarding; poor basic personal hygiene; need of repairs to the house; unsanitary conditions and inadequate utilities.

House needing repairs was the most common form, followed by hoarding, while inadequate utilities were the least common.
## Referrals to Senior Case Workers
(HSE 2013)

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Referrals</th>
<th>%</th>
<th>Psychological</th>
<th>%</th>
<th>Self-Neglect</th>
<th>%</th>
<th>Financial</th>
<th>%</th>
<th>Self-Neglect</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>1840</td>
<td></td>
<td>26%</td>
<td></td>
<td>20%</td>
<td></td>
<td>19%</td>
<td></td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>2009</td>
<td>1870</td>
<td></td>
<td>28%</td>
<td></td>
<td>21%</td>
<td></td>
<td>18%</td>
<td></td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>2110</td>
<td></td>
<td>26%</td>
<td></td>
<td>21%</td>
<td></td>
<td>18%</td>
<td></td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td>2302</td>
<td></td>
<td>29%</td>
<td></td>
<td>21%</td>
<td></td>
<td>19%</td>
<td></td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td>2460</td>
<td></td>
<td>30%</td>
<td></td>
<td>21%</td>
<td></td>
<td>21%</td>
<td></td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>2013</td>
<td>2437</td>
<td></td>
<td>27%</td>
<td></td>
<td>22%</td>
<td></td>
<td>21%</td>
<td></td>
<td>19%</td>
<td></td>
</tr>
</tbody>
</table>

- **Total Referrals**: The total number of referrals made to senior case workers.
- **Psychological** and **Self-Neglect**: Categories of referrals.
- **Financial**: Category of referrals.
- **Self-Neglect**: Percentage of referrals in this category.
- **Financial**: Percentage of referrals in this category.
- **Self-Neglect**: Percentage of referrals in this category.
Consequences of Self-Neglect

- Risk of death increased by 16-fold (Dong et al., 2009).
- Substantial 1-year mortality on referral to Adult Protective Services (APS) (Dong & Simon 2013).
- Risk for nursing home placement (Lachs et al. 2002).
- Increased use of Emergency Department (ED) services (Dong et al. 2012a).
Antecedents to Self-Neglect

Empirical Research Findings

- Co-morbidities (e.g. Depression, Dementia, hypertension, stroke, reduced physical function, coronary artery disease, diabetes, functional decline etc.)
- Executive Dysfunction
- Altered Nutrition
- Alcohol/substance abuse
- Living alone
- Traumatic life history (e.g. abuse early years)
- Poverty/poor health care/poor social and family support more than mental incapacity (Choi et al., 2009).
- Older adults, and people with long standing chaotic lifestyles due to mental health issues and drug or alcohol abuse (Lauder et al., 2009).
- Poor Coping (Bozinovski, 2000 Gibbons 2009)
- Older age and mental status problems were more strongly associated with global neglect behaviours (Burnett et al., 2014).
Executive Function and Dysfunction

- Executive function (frontal lobe function) is necessary for planning, initiation, organisation, self-awareness and execution of tasks and is critically important for protection and safety and independent living. Executive dysfunction inhibits appropriate decision making and problem solving (Hildebrand et al. 2013).

Characteristics of Executive Dysfunction

- Inability to complete complex cognitive tasks (i.e. managing finances, identifying dangerous situations)
- Inability to maintain adequate hygiene or self-administer medications

(Royall et al., 2005, Dyer et al., 2007)
Assessment

What are the possible Causative Factors?

• Physical/Medical
• Psychological/Mental Health
• Home Living Environment
• Financial
• Social/Cultural
• What are the views of the client, family, friends and carers and wider community interests?
Capacity is a collection of skills:

- Memory
- Logic
- The ability to calculate
- Executive Function

• Capacity: complex attribute – ability to understand consequences of a decision but also ability to execute decisions and to adapt plans (Dyer et al., 2007).

**Decisional and Executive capacity**
• “Articulate and demonstrate” models of assessment (Naik et al., 2008)
Due Diligence in Adult Protective Services (APS) Practice

(Duke 2003)

- Know the client’s lifestyle and preferences
- Follow all reasonable leads
- Take all appropriate action in the pursuit of clients safety and well-being
- Know all applicable state and local policy and procedures
- Determine the underlying causes of (injuries) and self-neglect

Know the client’s lifestyle and preferences

Follow all reasonable leads

Take all appropriate action in the pursuit of clients safety and well-being

Know all applicable state and local policy and procedures

Determine the underlying causes of (injuries) and self-neglect
Responses and Interventions

- No gold standard
- Comprehensive holistic assessment
- Building relationships
- Multi-agency work is key
- Awareness of local and national policy and legal frameworks
- Impact of behaviour on others e.g. children and neighbours
- Person-centred care
- Support
- Practice development mechanisms to facilitate creative practice, and interagency systems for shared risk-management and decision making
- Context of balancing principles respect for autonomy, choice, control, and empowerment and a perceived duty to protect safety and preserve health and well-being on the other hand.
Interventions (HSE 2014)

- Self-Neglect Clients
  - 62% availed of a service
  - 27% declined service offered
  - 11% not offered any service.
- Home support and monitoring (dominant services offered).
- Provision of residential care increased from 8% (2012) to 12% (2013).
- Addiction and cleaning services.
- 191 self-neglect cases remain open (36%)
- Garda consultation occurred in 4%, Garda notification in 9% and legal action in 3% of cases.
• Man (aged 39) who had a history of anti-social behaviour, was well-known to health professionals, and had alcohol dependency problems. He was frequently offered help that, equally frequently, he refused.

• Agencies and multi-agency network failed to recognise his degree of vulnerability and missed opportunities to intervene and support him in relation to his self-destructive lifestyle.

• The constant and inappropriate use of emergency and health services was seen as a nuisance and time wasting rather than what the frequency of the demands might signify.

• The absence of a clear disability or diagnosable condition created significant problems of ownership between agencies, with advice to referrers to seek help elsewhere rather than taking responsibility for finding a solution.

• Some records of agency involvement were missing.

• Agencies did not appreciate that attacks against his property might have been motivated by racism or his perceived disability (Braye et al., 2013, p.23).
Serious Case Review
BD (Dudley SVAB, 2010b)

• Agencies and multi-agency network:
• Failed to recognise degree of vulnerability
• Missed opportunities to intervene and support him in relation to his self-destructive lifestyle.
• The constant and inappropriate use of emergency and health services was seen as a nuisance and time wasting rather than what the frequency of the demands might signify.
• Absence of a clear disability or diagnosable condition created significant problems of ownership between agencies.
• Some records of agency involvement were missing.
• Agencies did not appreciate that attacks against his property might have been motivated by racism or his perceived disability (Braye et al., 2013, p.23).
Serious Case Review: Recommendations

- Record keeping (chronologies of agency involvement, co-ordinated record of involvement to identified needs and responses)
- Shared Computerised record of safeguarding team
- Developing policies regarding high and repeat usage of services
- Agreeing procedures about managerial oversight of complex cases and lead responsibility within and across agencies
- Implementing minimum levels of training
- Greater staff awareness of harassment hate crime and responses
- Promoting importance of assessments that identify predisposing issues behind the presenting behaviour

(Braye et al., 2013, p.24).
Case Study 2

- Ann, was a nurse and single parent, and in her mid-40s when she died as a result of pyelonephritis, urine infection and kidney stones (Sheffield Adults Safeguarding Partnership Board, 2009). Ann was a wheelchair user for many years, with limited mobility and had a range of health concerns: muscular spasms, physical impairments and intermittent speech loss. She was known to health and social care professionals for over 7 years and had over 900 interventions designed to assist her, and to support her in caring for her child (although her child was eventually taken into care). She persistently refused to engage with service personnel, either not allowing them access to her home or refusing to allow them to attend to health routines, personal hygiene and living circumstances unless under her exceptionally stringent conditions.

(Sheffield Adults Safeguarding Partnership Board 2009).
Serious Case Review: Recommendations

• Staff given support (individual and peer supervision, opportunities to debrief) interventions

• Senior manager should be allocated to lead real-time management of risk

• Regular checks decision-making ability and mental capacity when regularly refusing support

• Information sharing procedures should be reviewed.
Summarise and Conclude

• No agreed standard definition for self-neglect
• Self-neglect is a complex multidimensional phenomenon
• Relationship-building skills and a client-centred approach
• Assessment (e.g. capacity, self-neglect assessment tool, etc.)
• Effective multidisciplinary working.
• Multiplicity of interventions
• Self-Neglect Training and Practice Development
References


References

References


