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Self-Neglect: a case study and implications for clinical practice

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ABSTRACT

Self-neglect is a worldwide and serious public health issue that can have serious adverse outcome and is more common in older people. Cases can vary in presentation but typically present as poor self-care, poor care of the environment and service refusal. Community nurses frequently encounter self-neglect cases and health and social care professionals play a key role in the identification, management and prevention of self-neglect. Self-neglect cases can give rise to ethical, personal and professional challenges. The aim of this paper is to create a greater understanding of the concept of self-neglect among community nurses.

KEY WORDS

Self-neglect *Public Health Nurses * District Nurses * Community Nurses *Older People

Introduction

Self-neglect is described as a person's inability to provide for oneself the goods or services to meet basic needs (Day 2012). Self-neglect is mainly hidden and under-reported, which makes determining its prevalence difficult. In addition, it affects primarily older people, increasing with advancing age and more common in older men (Dong et al, 2012a). Furthermore, differing definitions have contributed to an underdeveloped epidemiology of the condition. Evidence is limited and data from primary care GP caseloads in Scotland suggests that prevalence rates vary from 166 to 211 per 100,000 populations (Lauder and Roxburg, 2012). No data are available in England (Lauder and Roxburg, 2012). In Ireland self-neglect cases account for 20% of the referrals received by specialist senior case workers who work specifically with elder abuse services (Health Service Executive 2014).

In the United States (US) the majority of people who self-neglect are community dwelling older adults and it is associated with deficits in physical, psycho-social and environmental factors (Iris et al, 2010). The most common mental health issues associated with self-neglect are depression and dementia. These can impact on decision making capacity (also known as executive function). Self-neglect is also associated with poor social engagement and high levels of alcohol abuse both in Ireland and the USA (HSE 2014, Spensley, 2008). Living alone, isolation, poor social networks and economic decline has the potential to increase risk and vulnerability for self-neglect (SN) (Day et al, 2013; Iris et al, 2010). Many risk factors are associated with self-neglect and these are presented in Box 1.

Box1: Risk Factors

- Cognitive impairment (e.g. depression, dementia, executive dysfunction etc.)
- Hypertension
- Nutritional Deficiencies
- Alcohol/substance abuse
- Living alone
- Traumatic life history (e.g. abuse early years)
- Poor social support
- Poor economic circumstances
- Deprivation (Lauder and Roxburg, 2012)
- Poverty/poor health care/poor social and family support more than mental incapacity (Choi et al, 2009).
- Life course 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).

Community nurses (Public Health Nurses and district nurses) have a key role to play in identification of vulnerable adults and people at risk of self-neglect. Self-neglect cases are viewed as a 'grey area' (Gunstone, 2003) that is frustratingly challenging for professionals in England, USA and Ireland (Torke and Sachs, 2008; Bartley et al, 2011; Day et al, 2013; O'Brien et al, 2014). Self-neglect is a serious public health issue that has many adverse outcomes. These include mortality, high utilization of health care resources and elder abuse as presented in Box 2.

Box 2: Adverse Outcomes and Self-Neglect

- Elder self-neglect is associated with poorer health (Dong et al, 2010b) and increased mortality (Reyez-Ortiz et al, 2014).
- Individuals who self-neglect display problems with executive functioning (EF) (Pickens 2013) and EF is associated with risk for self-neglect (Dong et al, 2010) and harmful outcomes (Tierney et al, 2007).
- Self-neglect is associated with increased use of health care services i.e. nursing home placement (Lach et al, 2002), hospice care (Dong & Simon 2013), hospitalization (Dong et al, 2012b) and emergency department (ED) visits (Dong et al, 2012c).
- The annual rate of hospitalization for reported self-neglect participants was significantly higher compared to participants without self-neglect (Dong et al, 2012b).
- Elder self-neglect was linked to increased risk for subsequent caregiver neglect, financial exploitation and multiple forms of elder abuse (Dong et al, 2013).

This article will highlight the complexity of self-neglect and the challenges encountered. The objectives are:

- To use an existing Irish case study to illustrate the complexities of managing a case of self-neglect that spanned a three year period
- To analyse the case to demonstrate how the case was managed and the outcomes achieved.

In order to address these objectives required the case is presented, including the history, the assessment and management/therapeutic interventions. This is followed by a discussion, including implications for clinical practice and a conclusion. An outcome of this approach is

the generation of new knowledge from this real case, which is transferrable to many other community nursing settings.

The aim of the case history is to convey the complexity of a self-neglect case and the interventions undertaken by a community nurse in this case a Public Health Nurse (PHN) in Ireland working with a multidisciplinary team over a lengthy intervention period. The outcomes achieved are outlined and this is followed by a discussion which incorporates aspects of the case for illustration purposes.

Case history and assessment

Tom [1] is a 61 year old single man who had always lived alone in his own home in a rural community in Ireland. Contact with health services commenced after neighbours raised the alarm as they had not seen Tom for 3 days and were concerned for his safety and welfare. They contacted the local police and Tom was found in a collapsed state in his house and was subsequently transferred to hospital by ambulance. A medical diagnosis of carbon monoxide poisoning was made. Following hospitalisation and a short convalescence, Tom was discharged home and a referral was made to the Public Health Nurse (PHN).

At this time the PHN conducted a home visit and undertook a holistic assessment (physical, psycho-social and environmental). She found that Tom was independent, able to drive and had a part time gardening job. The Mini Mental State Examination (MMSE) (Folestein et al, 1975) score was normal at 27/3030 and Tom had no previous history of mental illness or addiction issues. He has a distant cousin, but by mutual choice there is minimal contact. Observations of the home environment identified that it was dirty, neglected and in need of repairs. The cause of the carbon monoxide poisoning a faulty chimney had been repaired prior to hospital discharge. In consultation and agreement with

[1] This is based on an actual case history, however all names and non-essential details have been changed for client confidentiality

Tom, a Home Help (HH) service was put in place for 4 hours a week to provide light housework. However this was discontinued by Tom 2 weeks later. He may have perceived the service as some form of surveillance. Ultimately Tom declined any further intervention from the PHN or Home Help (HH) at that time.

Over the next 2 years, the PHN met with Tom informally in his local area. She stopped and talked to him and asked him how he was. The response was *"I am fine, I know where you are if I need you".* Two years after her initial involvement, she observed that Tom's mobility was deteriorating and his gait seemed unusual. She contacted the GP who made an appointment with a neurologist. The PHN consulted Tom and following lengthy discussions Tom verbally gave informed consent for PHN to seek support from his cousin Mary. Mary encouraged Tom to attend medical appointments and provided transport for these visits. Tom's sole income was odd gardening jobs so the PHN liaised with the Community Welfare Officer (CWO) and an application was made for the provision of a social welfare payment.

Case note review and assessment

Following a referral from a concerned neighbour, the PHN conducted a case note review which at this point, was eight months later. This holistic assessment of Tom encompassed physical, psycho-social and environmental needs. From this assessment it was established that, socially Tom was no longer engaging with people; there was no phone in the house and he had increasingly isolated himself from his neighbours and refused the PHN entry to his home. Numerous attempts were made by the PHN and Home Help to negotiate entry to Tom's house. After three weeks Tom agreed to allow the PHN entry. A home assessment revealed severe environmental neglect. The paint and wallpaper were peeling, water dripping down the walls and with evidence of mould and mildew and floors were sticky. There was a strong odour of urine and the bed was covered in human excrement.

Rubbish and debris were littered about the house and the little food in the house was mouldy and rotten and the fridge was not working. The house was cold and damp and there was no heating. The electric heater and coal that were supplied by the CWO were not being used. There was also evidence of a recent fire as the living room was blackened and scorched.

On physical observation of Tom, it was noted that Tom was unshaven; had visible facial sores; finger nails were long and dirty; an odour of urine and his hair was matted. This revealed neglected personal hygiene. He was wearing insufficient clothing for the seasonal cold weather. It was obvious that Tom had experienced significant weight-loss since the PHN had last seem him, 8 months earlier. Psychologically, Tom was slow to engage, he kept head down when conversing and his mood appeared low. He appeared to have a poor understanding in relation to the health and safety issues of his situation. Apparently Tom had tried to dry his urine-soaked mattress with the electric heater and this had resulted in a fire which fortunately, had been confined to one room.

The social, environmental, physical and psychological features in this case are typical of self-neglect case. To summarise the assessment, a medical diagnosis of Bilateral isolated lesions of globus pallidus (Kuoppama'ki et al, 2005) had been made during the neurological assessment in the preceding months as result of brain hypoxia or carbon monoxide (CO) poisoning. Damage to the globus pallidus can lead to movement disorders, jerkiness and involuntary muscle tremors. Carbon monoxide poisoning can result in respiratory and cardiac problems, brain damage and long-term health problems (Fisher et al, 2014). A total of 50 accidental poisoning deaths from carbon monoxide were recorded in England and Wales in 2011 (Gas Safety Trust 2011; Fisher et al, 2014). Community nurses need to undertake an assessment and critically evaluate risk and perceived needs and decision making capacity of client focusing on best interest of the person. The nursing diagnoses as assessed by the PHN over the lengthy period of her involvement are detailed in Box 3.

As Box 3 indicates, there are many nursing diagnoses which were managed at various times and stages by the community nurse during her involvement with Tom.

Box 3: Nursing Diagnoses

1. **Self-care deficit**[2] in relation to maintaining home environment: the house was neglected and in need of repair.
2. **Self-care deficit in relation to managing finances and economic problems were a barrier to maintaining healthy behaviours.**
3. Extreme self-neglect: home environment was unkempt, poor personal hygiene
4. Self-care deficit in relation to maintaining personal hygiene
5. Self-care deficit in relation to maintaining continence for both urine and faeces
6. Inability to maintain the ideal nutrition related to inadequate food and drink intake and knowledge deficit
7. Altered and impaired mobility
8. Potential for fall and fractures related to diagnosis of globus pallidus
9. Potential for impaired skin integrity related to incontinence, skin lesions and self-neglecting behaviours.
10. Inability to identify, manage, and/or seek help to maintain health
11. Self-care deficits in relation to coping.

Management and therapeutic interventions

While the PHN respected the autonomous choice made by Tom in refusing many home visits the PHN also recognized Tom's vulnerability and continued with efforts to engage with him

[2] Terminology relating to Orem's Model used as this is the guiding theory for public health nursing

and offer services. In seeking to establish a therapeutic relationship she explored various options and negotiated with Tom and coaxed him to eventually agree to a home visit and assessment. A person's decision making capacity is very important and to ensure Tom's decision making was informed the PHN made him aware at all stages of the case of the possible risks, benefits, possible alternatives and consequences of service refusal. Building up a quality relationship with Tom was critical in light of his poor social support networks and his identified needs. The PHN and HHC approach to Tom was sensitive and care approaches recognised 'choice', 'best interest', 'autonomy', 'self-determinism' in the context of expressed goals, protection and safety issues.

The PHN was previously able to make some progress with referral interventions such as nursing diagnosis #2 above. Tom had had no income other than what he earned from the odd gardening jobs. As a result of a PHN referral to the CWO, Tom was able to avail of social welfare benefits and receive supplementary funding for some equipment.

The PHN made progress in obtaining a medical diagnosis for Tom by approaching his next of kin and arranging for transport support to attend a range of appointments. Tom's case was discussed at the Primary Care Team (PCT) Meeting. The PHN referred to and collaborated with the General Practitioner and neurologist in achieving this intervention.

When Tom's condition reached crisis point the PHN and Home Help Co-ordinator still had to undertake a number of joint home visit before Tom was receptive and granted permission for them to enter his home. Following assessment the PHN & HHC went immediately to the GP Surgery to recommend admission to hospital for acute assessment of his physical and mental health status. The weather was extremely cold and the PHN assessed that he was high risk for of collapse and death and required urgent intervention.

Outcomes

Tom was admitted and remained in hospital for 4 months. A planned discharge meeting between hospital and PCT was conducted. Alternative sheltered accommodation in his local town was identified. Tom was assessed as being able to make his own decisions and was discharged home. The PHN continued to manage Tom case and he continues to receive high support from PCT and multidisciplinary team members. He has home help support three times a day. Staff in the sheltered accommodation supervises Tom with regard to his attendance for meals in the main centre and hospital appointments. The community psychiatric nurse attends to his mental health and medication needs. The local community look out for him while maintaining dignity and respect for him. He takes a daily walk around the town. Tom's past interests were reading, gardening and singing. Gradually with support from PCT and community Tom is currently helping with gardening in the local hospital. Tom attends the local library and has recently joined the choir in the local church.

Discussion

This section presents a discussion on the implications for District Nursing and Public Health Nursing Practice. As professional's community nursing practice is framed in their professional Code of practice (Nursing & Midwifery Council (NMC), 2008; Nursing & Midwifery Board of Ireland (NMBI), 2014). Community nurses require knowledge of procedural guidelines and safeguarding policy and empirical evidence to inform best practice, risk assessment, decision making and person-centered approaches to management of self-neglect cases (Braye et al, 2015; Day and McCarthy, 2015). Many risk factors are associated with self-neglect and are outlined in Box 1. Interventions used by community nurses in practice can be articulated by using elements from the public health nursing Intervention Wheel (Minnesota Department of Public Health 2001; McDonald et al, 2015). Decision making is a component of public health nursing practice (Nic Philibin et al, 2010).

Clinical decisions and judgements about the management of self-neglect cases can differ between professionals and are influenced by culture, beliefs, knowledge, experience, education and organisation (day et al, 2013). In handling self-neglect cases community nurses need to be knowledgeable on national and local policy and legislation on self-neglect. Service refusal is common among people who self-neglect. Bergeson (2006) inferred that accepting refusal of services could be viewed as client abandonment. Trespassing without permission may infringe owner's right and run risk of criminal charges (Ballard 2010). In addition, home surveillance visits without a clear purpose can stigmatize self-neglecting clients (Ballard 2010).

Assessment and determination of capacity will be central to any interventions used by community nurses. Person-centeredness and application of ethical principles to self-neglect case will enable community nurses to make judgments taking into consideration best interest and respect for the person (NMC, 2008; Ballard 2010; NMBI, 2014). Tom was under 65 years old, which is not unusual in cases of self-neglect. Consequently, Tom did not come under the remit of senior case worker (SCW) or elder abuse services who take referrals when there are allegations of extreme self-neglect (HSE, 2012, HSE 2014). There were no social workers for older people in the area; therefore while the SCW was consulted, the PHN took the lead role. Building therapeutic relationship with self-neglecting clients and sensitive comprehensive assessment are key to evaluating vulnerabilities (Dong and Gorbien, 2006; Day and Leahy-Warren, 2007; Braye et al, 2011). According to Dong and Gorbien (2006) priority should be given to:

- Listening to client's history and story;
- Reflection time to explore multiplicity of ethical issues from the perspective of self-neglecting clients and PCT.

Seeking to understand self-neglect from the clients' perspectives is very important (Band-Winterstein et al, 2012, Day et al, 2013). Valuing client confidentiality and respecting clients' wishes is paramount when it comes to sharing information with clients' family, professionals and other agencies (Ballard 2010). Critical thinking and collaborating with PCT enables community nurses to establish a plan of care that will be in the best interest of client (Dong and Gorbien, 2006). Good record keeping which chronologically details individual team member's and organizations involvement with self-neglect case (Dudley Safeguarding Vulnerable Adults Board 2010). This includes detailed assessment, identification and management of risk, interventions and evaluation of outcomes. Ongoing assessment and management of risk as is a multidisciplinary approach.

Tom requires ongoing support to enable him to remain in the community. The PHN will continue to manage; monitor and co-ordinate Toms care and liaise with multidisciplinary PCT. The case of Tom had a good outcome. However the outcomes of self-neglect cases are often poor and are associated with high relapse and high mortality (Dong et al, 2009) and increased risk for elder abuse (Dong et al, 2013). Caseload demands and resource constraints can lead to de-prioritization of self-neglect cases (O'Donnell et al, 2010). Community nurses and social care professionals have a pivotal role to play in the early identification and assessment of people who are living in hazardous environments and engaging in dangerous self-care behaviours (Lauder et al, 2006; Lauder et al, 2001). A range of PHN interventions were used in the management of Tom. These included establishing caring relationships with Tom, collaborating with PCT and advocating with services (Institute of Community health Nursing (ICHN) Population Health Interest Group, 2013). In this case Tom was unable to care for himself due to impairments in a number of areas. The therapeutic relationship built up over time with Tom, inclusion of Tom in decision making and negotiation were key factors in the outcomes achieved.

No objective self-neglect measurement tool was used by the PHN. An objective self-neglect measurement instrument is needed to guide assessment and interventions in relation to self-neglect (Day 2014). To support self-neglect practice, skills and knowledge development is essential and case studies and serious case reviews and research evidence on self-neglect can be used to support skills development (Braye et al, 2013). Staff supervision to support theory to practice and workforce development need to be prioritized by organisations (Braye et al, 2015; Braye et al, 2013).

Conclusion

Self-neglect is a complex multidimensional phenomenon encountered by community nurses. Many self-neglect cases such as Tom's can create ethical dilemmas and challenges for community nurses. This paper has used a real case study to clearly articulate the complexity of issues that can surround a case of self-neglect in the community and the individualised care planning required as a consequence. Initially, community nurses need to be knowledgeable of legal and policy issues. Serious case reviews and case studies can be helpful in supporting community nursing skills and knowledge development for self-neglect practice.

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LEARNING POINTS

- Self-neglect is a serious and complex public health issue, and ageing demographics will potentially increase risk for self-neglect
- Self-neglect cases present many challenges for community nurses and require a multiplicity of interventions
- Community nurses need to be knowledgeable about legal issues and safeguarding vulnerable persons policy and procedural frameworks for adults at risk of abuse and self-neglect
- Case studies, serious case reviews and staff supervision can be used to develop self-neglect practice.

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