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Housing and self-neglect: The responses of health, social care and environmental health agencies

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Abstract
Substantiated cases of elder self-neglect have been reported to be more common than either elder abuse or neglect. It is a problem that often requires the active involvement of a whole range of health, social, housing, police and voluntary agencies. The ways in which these various agencies respond to self-neglect and how they interact with one another is not known. This research explored the ways in which different health and social care organizations respond to the problems associated with self-neglect. Research methods involved qualitative in-depth interviews with housing, healthcare, environmental health and social workers and a sample of their clients who were described as living in self-neglecting circumstances. This study revealed a lack of joint working across the relevant professions in relation to self-neglect. Better co-ordinated intervention could improve effectiveness and help make available resources go further. The study also suggests a need for a preventative approach to self-neglect, although further work would be required to develop indicators for early intervention.

Keywords: *Self-neglect, Diogenes Syndrome, interdisciplinary working, housing, mental illness*

Introduction

Self-neglect is a complex and problematic phenomenon that can be understood within a number of competing discourses. In the UK, the dominant construction sees self-neglect as a medical psychiatric diagnosis. Self-neglect within this discourse is the product of an underlying mental illness or pathological personality process (Lauder, Anderson, & Barclay, 2002). In the USA self-neglect is conflated with abuse and neglect and self-neglecters are frequently described within the language of ''victimhood'' (O'Brien, 2001). These perspectives have been challenged by Lauder (1999a) who proposed that self-neglect is a social construction which must be understood with a culturally-bounded discourse on hygiene and cleanliness norms and values. A more recent development has seen self-neglect described within self-care theory (Lauder, 2001). Self-care theory broadens the concept to include neglect of health-related behaviours. Self-neglect within this theoretical framework can be described as not engaging in those self-care actions that are required to produce socially acceptable levels of personal and household cleanliness and personal health and wellbeing (Lauder et al, 2002).

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Given the difficulties in conceptualizing self-neglect it is not surprising that there is little epidemiological data on its prevalence and incidence. The most comprehensive epidemiological studies have been conducted in the USA and whilst this data must be generalized to the UK with caution, it remains the most reliable data available. The National Elder Abuse Incidence Study (NEAIS) reported that the incidence of elder self-neglect in USA is higher than that of both elder neglect and elder abuse (National Centre on Elder Abuse, 1998) with 57,345 substantiated cases of self-neglect reported to Adult Protective Services (APS) agencies and an additional 81,635 substantiated cases reported by sentinels (specifically trained community agency personnel) in 1996 alone. This study supported the ''Iceberg'' concept of self-neglect and it is estimated that for every substantiated case there are as many as five others which are unknown.

However, despite the size of the problem and the fact that self-neglect presents many difficulties for health and social care organizations (Lauder, 1999b), relatively little research has been conducted on interventions for self-neglect and there are few examples of good practice for staff working with clients who self-neglect. The development of interagency guidelines is an especially difficult exercise given the fact that a range of professions and organizations are frequently required to respond to self-neglect. Self-neglect is a classic example of a human problem which falls into that grey area between health, social work, housing services and environmental spheres of influence. There is still much we do not know about self-neglect and the type of services which produce best outcomes for self-neglecters.

Self-neglect has been most frequently discussed in medical literature. A number of labels have been applied such as Senile Breakdown (Macmillan & Shaw, 1966), Diogenes Syndrome, (Clark, Manikar, & Gray, 1975) and Social Breakdown (Ungvari & Hantz, 1991). Individuals who self-neglect are reported to live in unclean, verminous circumstances, often associated with hoarding, large numbers of pets, structural deterioration of the property, and bizarre lifestyles or behaviour (Snowdon, 1987). Stories about self-neglect are, from time to time, documented, even sensationalized, in visual and print-based media. Alan Bennett's *The Lady in the Van* tells the story of an eccentric woman who moves into a quiet street in Camden Town. She lived in her van until Camden Council forced her to move on. Bennett allows her to live in his garden for the next 15 years (Bennett, 1989).

Self-neglect is associated with a high incidence of mental and physical disorder (Halliday, Banerjee, Philpot, & Macdonald, 2000), although around 50% of self-neglecters have no diagnosed mental illness. Abrams, Lachs, McAvay, Keohane, & Bruce (2002) suggest that depression and cognitive impairment may be precursors of self-neglect in the elderly and these may be seen as early warning signs. A self-neglect referral to Adult Protective Services in the USA is a stronger predictive factor for nursing home placement than medical, social and functional factors (Lachs, Williams, O'Brien, & Pillemer, 2002).

Lauder (1999b) has previously shown how health service delivery is often fragmented and uncoordinated. Halliday et al. (2000) also suggest that there may be deficits in care provision and advocate for a more assertive treatment approach. In their survey of ''service refusers'' in Dublin, Hurley, Scallan, Johnson, & De La Harpe (2000) found that a wide variety of services had been offered to this group (most of whom were self-neglecters), including home help and house cleaning. Over 50% of service refusers had not been offered a service that Hurley et al. believed could be described as having successful outcomes.

There is a sense of therapeutic pessimism evident in both the literature and the attitudes of professionals on the ground (Lauder, 1999b). It is therefore important to discover and report examples of good practice. The academic literature provides little help in identifying effective interventions for people who self-neglect. Previous studies have largely been

restricted to people presenting to health care services (Gannon & O'Boyle, 1992). There has been little discussion of self-neglect in the broader social science literature or in relation to local housing, social work and environmental health services.

The qualitative study sought to explore the various ways in which different agencies respond to self-neglect. The study aimed to describe the ways in which self-neglect is understood by professional agencies and how this influences interventions provided by these agencies.

Research design and methods

The design involved the use of in-depth interviews with health, social work, housing, environmental health professionals and self-neglecters. In-depth interviews were selected to explore the ways in which these various agencies respond to self-neglect. Validity was ensured by providing a thick description of data for public examination, presenting preliminary analysis at a stakeholder workshop for expert scrutiny, and team analysis (the research team comprised housing, psychology and nursing academics) in what was in essence a form of inter-disciplinary triangulation. Ethical approval was obtained from relevant ethical committees.

Sampling plan

The difficulties in identifying and recruiting self-neglecters and those who provide services for them via local government agencies necessitated a time and labour intensive sampling process. A three-stage sampling strategy in two local government areas in Scotland was employed:

(1) Recruiting housing and social work managers in each area. These key informants had been identified by the senior manager in each area. In turn these managers identified fieldworkers from their relative departments.
(2) Fieldworkers would then identify cases of self-neglect based on the definition provided by the researchers. These workers often provided very rich initial written data on each specific case.
(3) Using a snowball strategy to identify other professionals involved in individual cases (e.g., health and social care workers).

The Social and Healthcare sub-sample comprised of 12 Housing Officers, three Environmental Health Officers, 13 Social Workers and three Healthcare Workers and six clients. Workers identified all clients who met the criteria for self-neglect used in previous studies (Lauder, 1999a). Data on a larger number of clients ($N = 62$) was also collected from professional interviews of all the sub-sample and from background information provided by fieldworkers.

Data collection and analysis

Interviews were conducted with workers at their place of work, or in their home in the case of clients and they usually lasted for around one hour. All data were audio-recorded and fully transcribed for analysis. Data were firstly analysed independently by each member of the researcher team. Subsequently individual analyses were compared, contrasted and refined in a group setting. The analytical method used was content analysis strategy of

deductive category application described by Ryan and Bernard (2002). Data were read and re-read with a view to eliciting their meaning. Techniques for discovering meaning in transcripts included identification of word repetitions, key-words-in contexts followed by the physical manipulation of entire transcripts by paper and scissors cut and pasting. Key data were summarized and grouped in meaningful categories that were then compared and contrasted by the research team. Data were subsequently linked to the specific research questions. Particular cases or quotations which illustrated key findings or succinctly summarized pertinent examples were also documented. The data were so rich as to defy reduction to a few ideas or themes, to do so would have meant a loss of data, which at this stage in our understanding of self-neglect would not be a desirable outcome. Data are grouped under headings for convenience and presentational purposes.

Findings

Circumstances of clients and properties

Many clients fitted the ''stereotypical'' images of self-neglect found in the medical literature in which houses were dirty, full of rubbish and in a general state of disrepair. Nevertheless, as expected, the full range of presentations provided a more diverse and varied picture of self-neglect. Cases of self-neglect included a small number of younger single women with children who lived in squalid conditions. This further challenges existing definitions of self-neglect and highlights the importance of further work focused on clarifying the concept and the identification of clusters and patterns within cases of self-neglect.

A number of clients lived in conditions of extreme disrepair with buildings in a state of collapse, holes in the roof, ceilings, walls and broken windows. Interiors were often sparsely furnished with bare floorboards and makeshift stoves/cooking facilities including open fires on the floor. In many cases there was no electricity, running water, or proper sanitation. Environmental health professionals, in particular, reported clients living with blocked toilets, offensive household odours, and infestations of fleas, flies, rats, and maggots. There were reports of large numbers of pets, particularly cats, within dwellings. A commonly reported feature involved houses being crammed full of belongings, which spilled over into the garden area. Such clients hoarded rubbish, clothes, newspapers, family belongings and miscellaneous items.

The analysis suggested a possible key distinction between hoarding behaviour and neglect of personal and/or domestic hygiene (although the two were not always mutually exclusive). In a number of cases self-neglecters, despite squalid living conditions, were reported to display levels of personal hygiene that equated to accepted social norms. It was not uncommon to find individuals who made a major effort to maintain their own personal hygiene, in one case using the local swimming pool for bathing and attending to other aspects of personal hygiene. This suggests that there may also be a phenomenological distinction to be made between neglect of housing and neglect of self. This finding supports the idea that self-neglect is not an all-or-nothing phenomenon and that in some aspects of their lifestyle, many individuals may have residual coping and self-care strategies.

Social contacts

Many clients were well known in the neighbourhood and perceived as ''harmless eccentrics''. Neighbours were often tolerant, even supportive of their self-neglecting neighbours, only getting involved when the situation was causing a nuisance, or they feared for the well-being of their neighbour. Neighbours were often primarily concerned regarding

smells, blocked drains, excess rubbish or perceived fire risks. There were some instances where neighbours had confronted the clients, occasionally resulting in aggression from one or both parties. A variety of events were found to trigger service intervention, with the trigger dictating which agency is first involved. It was believed that most clients came to the attention of agencies through neighbours' complaints to the police. While this was often the case, housing officers would also discover self-neglect on home visits to discuss rent arrears or housing repairs. Invariably agencies became involved at a relatively late stage when relationships had broken down and the potential for successful interventions was diminished.

A small sub-group of self-neglecters had lived their adult lives with family members, and subsequent self-neglect can be linked to the death of parents or siblings. This may be explained by the failure of such individuals to fully develop self-care agency. Self-care agency is a developmental set of abilities that enable individuals to see and understand events and actions that must be controlled or managed in order to regulate their own functioning and development as well as the ability to decide about and undertake adequate self-care actions (Soderhamn & Cliffordson, 2001). Self-neglecters have been shown to have less developed self-care agency than matched cases (Lauder, 1999). However, in a small number of other cases self-neglect was linked to a family history of this lifestyle. Self-neglect in these instances appeared to be a learned pattern of behaviour and values. Clients were not necessarily confined to their dwellings and many regularly went out and about in the local community. In some cases, abuse by others was apparent (e.g., neglect by relatives, harassment by local youths, acquaintances using homes as a drinking den). These clients often had a co-existing mental illness and were an especially vulnerable group.

Agencies found the issue of pets difficult to deal with in a productive manner. In one example, getting rid of pets was a condition of rehousing. However, pets may be of central importance to clients as they are frequently the most important form of friendship and comfort to self-neglecters. The issue of pets should be taken seriously and should be taken into account when intervention plans are being developed.

Agency perceptions and intervention

Many professionals were confounded by the range and complexity of cases and for those encountering self-neglect for the first time, this was compounded by the lack of explicit guidance as to how best to intervene. Dealing with self-neglect seldom features in formal educational preparation. Professionals reported that accessing clients and their homes to be exceptionally difficult. Many clients did not open or read their mail and appointments were missed due to chaotic lifestyles. Even those professionals who were well regarded by their clients still found access difficult at times. This was seen as a form of withdrawal and was thought to be the client's way of dealing with the situation. In effect the client is viewed as making an active decision as to whether they should either seek or accept contact with the professional, but only on the client's terms.

Decisions regarding interventions were frequently taken without apparent regard for the client's wishes and even without their consent, for example clearance of a property by environmental health services. Such action could result in distress for both client and professionals. Some clients were initially agreeable to regular, low level support, but at a later stage refused this service expressing dissatisfaction at the intrusiveness, and the additional expense where they had to contribute to the costs for support they hadn't requested. Clients appeared to be merely ''tolerating'' much service input.

A key finding was the very clear link between intervention and formal psychiatric diagnosis. Such a diagnosis would trigger resources for a relatively comprehensive intervention from nurses, psychiatrists, allied health professions and support workers. The diagnoses rarely related to self-neglect (or Diogenes syndrome) itself but rather, clients were treated for a number of severe and enduring mental illnesses. Self-neglect was an associated, rather than a direct factor, in intervention. These clients had the widest support networks including psychiatrists, community psychiatric nurses, occupational therapists, and voluntary sector support workers, all of whom were co-ordinated through existing working practices. Clients cared for through this pathway were offered a relatively comprehensive care package. Examples of good practice, all of which were valued to some extent by the client, generally involved very practical forms of support including help with shopping, advice on completing forms and support with house cleaning. The key to clients accepting such support was the development of a good therapeutic relationship with a health or social care worker, which on many occasions was the least qualified support worker.

Where there was no psychiatric diagnosis, the rationale for intervention was much less comprehensive. Self-neglect was often considered a lifestyle choice and professionals did view self-neglect as being a problem of the client's making, rather than attributing this to also involve environmental or social causal factors. Without a medical diagnosis, clients were not offered specialist psychiatric health care and their access to social work or other support was also extremely limited. They were more likely to be the subject of enforcing intervention through environmental health or housing services.

On the whole, different professional groupings approached the problem of having to respond to self-neglect based on their own agency perspectives. Environmental health services employed powers of coercion to define self-neglect as a public hazard and thereby abate the nuisance; health and social care workers adopted a care and support perspective, using persuasion to alleviate the situation (but influenced by mental health diagnosis); and housing workers gave a high priority to the physical state of the property and tenancy matters such as rent and relations with neighbours. They used negotiation (containment) and enforcement (eviction) strategies. However, there were instances where housing and environmental health workers reported a therapeutic role beyond usual responsibilities. The therapeutic role of these professional groups needs further study, as they may be a resource that is not used to full effect.

Environmental health workers had the clearest remit for forced intervention in relation to abatement of a statutory nuisance and this eased the process of intervention for individual workers. In contrast, housing workers had much more discretion, for example in relation to containment of self-neglect in a deteriorating tenancy, versus eviction and rehousing, possibly to a different area or type of property. Many housing professionals accepted that eviction only moved, rather than solved the underlying problem, though it may offer an opportunity to make a fresh start with a social work supported programme in a different property. However, clients may genuinely enjoy living in a particular property, and feel further penalised when forced to leave.

The complexity of self-neglect necessitated multi-disciplinary working, but appropriate procedures rarely existed. This is best illustrated in a case in which housing professionals had to evict one self-neglecter due to poor tenancy and rent arrears. He was deemed to have made himself homeless and could not be rehoused by this department. The case was then referred to social workers in the same area who had to deal with the homelessness issue which was now superimposed on the self-neglect. Data revealed the limited knowledge which professions often had of each others roles and none had a ''comprehensive overview'' of the nature of the problem and the possible different interventions. Liaison between

professions was often *ad hoc* and dependent on the commitment of individual workers, rather than generally established procedures. Even the relatively co-ordinated mental health intervention pathway did not fully include housing and environmental health agencies.

Some cases were identified where enforced intervention had been followed up by appropriate support over the medium to long term. However, professionals reported frustration at not being able to resolve the situation and ''failing the client''. There was clearly an emotional cost to working with such clients. While intervention reflected both enforcement and support, many professionals were highly sympathetic to the circumstances of clients. A small number of cases necessitated a high intensity input and a high stress level for workers. Improved collaborative working might help to alleviate some of these pressures. Simply monitoring or maintaining the situation was felt to be time consuming and ineffective as a solution. Financial costs of clearances were rarely recouped from clients, due to their low incomes/lack of savings. Some clients were ineligible for services (such as grass cutting), which might have prevented more serious deterioration.

Conclusions

There was considerable divergence between client and professional perceptions, and also between professional groupings on the nature of self-neglect and how they should respond to this client group. Self-neglect is characterized by diversity, with few simple generalizations identifiable from the evidence. Some clients acknowledged a need for help but many wished to be left alone with their lifestyles, albeit, lifestyles of poor quality in relation to contemporary social norms. Client needs were diverse but it seems clear that their wishes about preferred interventions, insofar as the capacity to make their wishes known exists in each case, should be the starting point of any engagement with health and social care agencies.

All professions found self-neglect frustratingly difficult to deal with. It was difficult to access clients and to obtain their co-operation, and no single solution to dealing with self-neglect emerged. Housing and environmental health assumed a mainly controlling and monitoring role, viewed by clients as at best neutral, but often as negative. Social work and NHS professionals adopted what was a generally caring and supportive approach, more often seen as either neutral or positive by clients.

In this study the importance of mutual engagement in a therapeutic alliance was found to be central to effective interventions. Working relationships developed over time and no single profession had an absolute monopoly in this regard. The client's own perspective must be considered central to the development of this type of alliance. Where positive, therapeutic relations cannot be established, important issues relating to personal rights, vulnerability and statutory obligations provide an important safeguard for the client and professional alike.

Understanding self-neglect still requires a careful consideration of the fine balance of choice against consequence, at the point at which individuals' lifestyle choices become unacceptable because of risk to themselves or nuisance to neighbours. The diversity of cases is likely to require an individualised, rather than a generalised response. However, some general guidelines can be applied and professions could certainly be better informed about the nature and impact of self-neglect and the potential success of intervention.

Earlier literature suggested a close association between psychiatric illness and serious self-neglect (Shah, 1992; Wrigley & Cooney, 1992; Abrams et al., 2002). A key finding from this study is that a medical diagnosis significantly influences the nature and extent of health and social care intervention. Service provision is often denied to those with no formal diagnosis,

rather than being based on an objective consideration of the reality of their living circumstances.

Problems of co-ordinating multi-agency working across health, social work and housing have been well documented (Anderson & Barclay, 2003), though environmental health services have rarely featured in previous research. This study again revealed a lack of joint working in relation to self-neglect which could have made available resources go further and improve the effectiveness of intervention. Effective interagency working would be facilitated by reconstructing professional identities with a focus on mutual understanding and shared values and practises, establishing greater role clarity (King & Ross, 2003) and through creating more stable teams allied to a commitment to working with this client group (Cowley, Bliss, Mathew & McVey, 2002). More fundamentally, circumstances of self-neglect need to be firmly embraced as a legitimate indicator of need for support services, along with the other, better established, community care groups. Interventions in self-neglect should be incorporated into joint training initiatives between relevant agencies and should also be included in under-graduate training.

The evidence suggested that professional interventions are employed at a late stage when patterns of behaviour are well established and probably less amenable to change. This indicates the need to consider the potential for early intervention in cases of self-neglect. Early interventions in a range of mental health problems such as schizophrenia (Kasper, 1999) and post-traumatic stress in children exposed to violence (Stein et al., 2003) are linked to improved health outcomes. This would necessitate strategic responses to early warning signs and established triggers for intervention. These identifiable and potentially solvable problems include tenancy issues such as rent arrears or environmental health issues such as deteriorating household hygiene. In reality, effective multi-agency working at a later stage may prove more achievable than early detection. Many clients only come to the attention of services once self-neglect has become chronic. This pattern makes early intervention difficult. Future studies should seek to recruit more self-neglecters and allocate sufficient time and resources to this difficult task. The number of self-neglecters interviewed was a limitation of the study. Further work is needed to identify warning signs that may trigger earlier, but less draconian, interventions which may be more satisfactory to all parties involved. This would require much greater general awareness of self-neglect across local government professions and the development of an assessment tool that could be used by all professional groups. Educational provision should reflect the interdisciplinary, ethical and interpersonal aspects of care and should also target support workers as well as qualified professional groups such as social workers and nurses.

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