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Developing self-neglect theory: analysis of related and atypical cases of people identified as self-neglecting

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Self-neglect is a complex, relatively common and as yet not fully understood phenomenon. People who self-neglect often do not undertake those activities which are judged necessary to maintain a socially accepted standard of personal and household hygiene or to maintain their health status. This may be explained by a variety of factors of which psychopathology, culture, social class and poverty all play a role in the construction of this phenomenon. The self-neglect literature overwhelmingly presents professional views and focuses on the most severe cases. This paper explores some core issues in relation to self-neglect theory through in-depth interviews with atypical (related) cases. These cases allow the boundaries of what is and is not self-neglect to be tested. Analysis of these cases suggests that self-neglect remains a useful concept but contains a far wide range of presentations than previously reported.

Keywords: poverty, self-neglect, social exclusion, squalor

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Defining self-neglect

There is a degree of consensus in the international literature regarding the core features in the most severe cases of self-neglect. In this extreme end of the self-neglect spectrum, a constellation of behaviours are generally reported which include severe household squalor (Cooney & Hamid 1995), hoarding (O'Brien *et al.* 1999), poor nutrition (Smith *et al.* 2006), service refusal (Hurley *et al.* 2000), inadequate personal hygiene (Reyes-Ortiz 2001), medication mismanagement and poor health behaviours (Gibbons *et al.* 2006). Snowdon *et al.* (2007) have recently challenged this diagnostic consensus by arguing for a distinction to be made between severe domestic squalor and cases in which an individual may neglect self-care but who still manage to maintain their household circumstances in a reasonable condition. A second challenge to the diagnostic consensus comes from Pavlou & Lachs (2006). In what is possibly one of the more robust reviews in a field crammed with reviews and with a relatively small number of primary studies, they argue that self-neglect is a geriatric syndrome. This review included 54 papers and comprised 24 case series, 13 theoretical articles, 11 observational studies and six reviews, and they concluded these were of highly variable methodological quality. Pavlou & Lachs' claim for self-neglect to be a geriatric syndrome is based on its multifactorial aetiology, shared risk factors with other geriatric syndromes, association with functional decline and association with increased mortality. Self-neglect has significant implications for mental health nurses as around 53% of

people who self-neglect have a mental health problem (Dyer *et al.* 2007).

Deficient self-care is a facet of the self-neglect phenomenon that can go undetected until a pattern of behaviour is well established and detected by healthcare personnel (Gibbons *et al.* 2006). It is linked to chronic medical conditions (Abrams *et al.* 2002, Campbell *et al.* 2005) and nutritional deficiency (Adams & Johnson 1998) in someone with advanced age who lives alone. Payne & Gainey (2005) in a study of 751 cases referred to adult protective services (APS) in Virginia report that this group are less likely than other groups referred to APS to need assistance with toileting, eating and using the telephone.

A more functional and pragmatic approach to defining self-neglect suggests that we conceptualize this as a constellation of practical problems which health and social care workers encounter when working with this client group. From the perspective of the practitioner self-neglect may best be understood in terms of a set of complex and often poorly defined problems. Some of the main problems nurses encounter include identifying self-neglect in its early stages, making judgements of risk and initiating interventions in the absence of a substantive intervention-related evidence base. Gibbons *et al.* (2006) have published a proposed nursing diagnosis for self-neglect which implicitly reflects this pragmatic stance.

Epidemiology of self-neglect

Reliable data on the incidence of self-neglect are scarce and are usually derived from studies in the USA based on APS or the New Haven Established Populations for Epidemiologic Studies of the Elderly Cohort (Abrams *et al.* 2002). The APS in the USA are state-based statutory services that are responsible for investigating abuse, neglect and exploitation of adults who are elderly or have a disability. The APS in some states also provide case management, counselling and support services to adults who have been abused, neglected or exploited.

These data and much US data conflate self-neglect and neglect, and as a consequence the extent of self-neglect remains unclear. In Texas in 1997 over 62 000 allegations of adult mistreatment and neglect were reported to APS (Pavlik *et al.* 2001). The prevalence was 1310 individuals per 100 000 of the population aged $\geq$65 years for all abuse types. With this limitation in mind the state-based APS system in the USA has no real equivalents in other countries and may be the most comprehensive, enlightened and proactive system to be found. In the UK, the recent Protection of Vulnerable Adults legislation has been implemented, but it is noticeable how little self-neglect features in this initiative.

Self-neglect and comorbidity

People who self-neglect may have pre-existing mental and physical disorders (Halliday *et al.* 2000), although it is not clear whether this is a causal relationship. Abrams *et al.* (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. Campbell *et al.* (2005) propose a more ecological position, albeit still clinging to the personality hypothesis, when suggesting that self-neglect is triggered by biological, psychological and/or social stressors that exacerbate predisposing personality traits. Diagnoses that have been consistently associated with self-neglect either in a causal relationship or as comorbidity include dementia (Dyer *et al.* 2000, Lachs *et al.* 2002), alcohol abuse (Snowdon 1987, Payne & Gainey 2005) and major life events (Lauder 2001). The cases found in much of the literature tend to be based on presentations to healthcare services or APS and may represent a more severe end of the self-neglect spectrum.

Responding to self-neglect

Lauder *et al.* (2005) have proposed a framework for interagency services in cases of self-neglect. One legitimate criticism of this framework is that although putting self-neglecters needs at the heart of service delivery the voice of self-neglecters is missing. Hurley *et al.* (2000) describe self-neglecters in terms of service refusers. This unwillingness to wholeheartedly accept treatment and services is almost one of the defining features of self-neglect. Paradoxically, the refusal of services is a major issue in the delivery of services and should be a major goal in treatment. Interventions with this group involve a long-term commitment as self-neglect can be seen as a chronic and long-term condition. The likelihood is that one will not see a 'cure' or sudden and dramatic change in circumstances and often clients merely tolerate interventions, creating a difficulty for health and social care professionals in sustaining their commitment to maintaining a therapeutic relationship (Lauder *et al.* 2005).

Theory and self-neglect

There is still much scope for consensus building around definitions, theories and measurement of self-neglect (Gibbons *et al.* 2006). Theoretical perspectives include those emphasizing self-care (Rathbone-McCuan & Bricker-Jenkins 1992) and social constructionism (Lauder *et al.* 2002), although most studies found in the literature are atheoretical. One of the most obvious omissions from the literature is the perspective of self-neglecters themselves, probably because of the difficulties in recruiting this client

group. Very few studies actually interview and describe self-neglect from the perspective of those described as self-neglecting. Bozinovski (2000) in his grounded theory study suggests that preserving and protecting self and maintaining customary control are the two processes by which self-neglecters maintain some sense of meaning and continuity in their lives.

Although there is general agreement on what constitutes severe self-neglect the boundary between living a non-conformist lifestyle and a pathological state is blurred. Equally, the transition, if indeed there is such, between living a squalid but non-pathological lifestyle choice and severe self-neglect, as defined by clinicians and law makers, is difficult to logically sustain. Self-neglect diagnoses or classifications are based around the implicit notion of a threshold of behaviours, the crossing of which is abnormal (Lauder *et al.* 2002). As most studies of self-neglect have focused on severe cases the nature of that threshold remains vague, blurred and a matter for professional or legal judgement. There are very few studies which actually involve in-depth interviews with people who self-neglect and can facilitate greater understanding of the nature of the joint construction of self-neglect between the self-neglecter and the profession making the self-neglect diagnosis.

The literature reflects an ongoing debate regarding the theorization, causation, presentation, history and treatment of self-neglect. In the light of this debate, the study reported here aimed to explore the boundaries of self-neglect and contribute to a clearer theorization of this phenomenon. Specifically, the issues of comorbidity, history and self-neglect-abuse-hoarding conceptual boundaries will be explored.

Research methods

Design

This qualitative study sought to extend current self-neglect theory by eliciting the views of people who show some features of self-neglect but are not stereotypical cases. These cases are at the boundary of what can be described as self-neglect. The study involved conducting in-depth interviews with a theoretical sample of individuals identified by social care and voluntary agencies as being self-neglecting.

Sample

Sampling rationale followed the precepts of case construction in what is a modified concept analysis methodology. This involved recruiting a number of related cases (Walker & Avant 1995). Related cases are cases of a given phenomenon which are similar to the stereotypical cases or model cases, as Walker & Avant refer to them, of self-neglect but which differ in significant ways (Walker & Avant 1995). Related cases in concept development methodology are often manufactured cases and not real cases as reported in this study. We adopt the position that theory construction and concept development is an iterative process and that concepts cannot be analysed prior or independently to theory development.

The sample differed from stereotypical cases in respect to their younger age, being recruited through social and voluntary services and who were at an early stage in the self-neglect trajectory. Through exploring the characteristics and perspectives of this sample, the boundaries of self-neglect can be tested in relation to conventional presentations such as the relationship between self-neglect and comorbidity.

People who self-neglect are difficult to recruit, which bearing in mind their tendency to refuse services should not be seen as a surprise. Recruitment procedures followed those proposed by Barclay *et al.* (2002) in which local government social service agencies and voluntary agencies known to work with people who self-neglect were contacted and asked to facilitate access to participants. The research team would in the first instance meet with care workers to explain the project and describe the type of participant to be recruited. Workers would then identify and approach potential participants and ask if they wished to participate in the study. Participants were subsequently approached by the research team during which time information on the study was given, and a time and date for the interview were agreed. All but two potential participants who were approached agreed to participate.

Considerable effort was invested in working with local government agencies to gain their support. This proved both expensive and time-consuming. Trust was an issue for some local government services, and they were often suspicious about the purposes of this study and its implication for their service. This was interesting as it was a mirror image of the ways in which they were regarded by participants and may reveal an underlying structural problem in services to this client group.

Data collection and analysis

Data were collected by in-depth interview at a venue of the participants choosing. Interviews lasted between 30 and 90 min were audio-recorded and fully transcribed. Data were analysed using grounded theory methods (Glaser & Strauss 1967). The data were initially managed with the qualitative data package Atlas.ti (T Muhr 1997 Scientific Software Development, Berlin, Germany). Atlas.ti facilitated the research team to manipulate code and segment

data and to stimulate the generation of rich textual themes (Glaser 1965).

Two members of the research team independently analysed and coded transcripts. They then compared and agreed final themes. A third member of the team confirmed themes by undertaking a further independent check of the transcripts.

Analysis involved comparing the phenomenon as described by participants with the theory context of self-neglect as outlined in extant literature (Strauss & Corbin 1997), through the systematic search for causal conditions and phenomena–context interaction and the consequences of interventions. The end point in this study was not to develop a theory of self-neglect as this was too ambitious for a single study with 10 participants.

Ethical approval

Ethical approval was obtained from the relevant university ethics committee.

Informed consent was gained by providing all participants with written information on the study. This was further expanded through a verbal explanation provided by both the researcher and the professional who had initially recruited the participant. All participants were required to give written and informed consent.

Findings

The main themes from the data included self-neglect, comorbidity, history, self-neglect, abuse and hoarding.

Data on 10 participants were obtained. Participants in this study included three women and seven men with the age of participants ranging from 24 to 73 years old. A number were homeless and being cared for in Salvation Army facilities while others remained in social housing in relatively deprived communities in Scotland. Those in social housing were all young women who were currently in relationships and had children living at home.

Self-neglect and comorbidity

All participants reported the presence of one or more relatively serious health problem, ranging from alcohol and drug addictions to severe and disabling physical conditions. In several cases, participants detail poor health including hip replacements and respiratory problems:

> I have advanced osteo-arthritis, cervical spondylosis and arthritic hip. I'm waiting on a new hip replacement. (Participant 4)

and

> I took pleurisy and pneumonia and that's when it came out I smoked heroin. (Participant 5)

Other comorbidities included self-harm, depression and violence. The well-established link between self-harm and abuse in women (Harris 2000) was also evident with one woman stating:

> The self harming got worse when I took one of the men to court 2 years ago (for domestic violence). (Participant 5)

Participants highlighted a number of substance dependency issues that their thoughts played a causal role in their self-neglect. Alcohol figured largely in these accounts. This association is evident in the literature (Snowdon 1987). The alcohol-self-neglect link was the strongest theme in the data set. Substance dependency appears in this sample to have a central position in the generation of problems such as self-neglect which in turn leads to more acute social problems such as homelessness. One respondent succinctly illustrates the possible cyclical nature of substance dependency, self-neglect and homelessness:

> I was going to go to prison. See I was 10 years in prison, and came out and got a house. Well I went into (name of hospital) it was for people who drink, a hospital. I lost the house. I'm afraid I got put out of there. (Participant 3)

What is evident in all the cases in this study was a picture of chaotic lifestyles, attempts at reform, spirals of substance dependency and the inability of statutory services to cope with people on such trajectories. Of the key interview participants, four had serious issues with alcohol that had left indelible marks upon their lives. Interestingly, a majority of these subgroups data were cross-coded with the themes of 'loss', which included loss of house, family, self-respect, as well as jobs and other markers of social enterprise:

> Well put it this way when I was in my old house I really needed help.
>
> Well if I had have stayed in my old house I would . . . I was drinking too much and I was a total shithouse and I would never have been able to live there. (Participant 4)

and

> Within a year I would have probably been out on the streets. But with the help of ⟨support worker⟩ and her colleagues from ⟨religious charity⟩ I've managed to get back on my feet. I've got all my debts cleared and everything else. That's the way it is going to stay. (Participant 4)

Interestingly, the latter quote demonstrates the programme of intensive social support given through religious charities, which in some instances appeared to enable clients to recover their sense of self-worth. For other participants, illicit drugs were highlighted as major contributing factors in the spiral of self-neglect.

History of self-neglect

Most participants detailed fractured personal biographies in which chaotic lifestyles featured prominently. People who are forced to move or who become homeless frequently fall victim to substance dependency and abuse. Occasionally, this appeared linked to proximity to others who are substance-dependent. Many participants seemed to have a peripatetic existence:

> I just got fed up and started travelling. (Participant 6)

and

> I would stay for 2–3 weeks something like that and would 'sign on' for that time and then I would go again. (Participant 1)

Other participants' stories detail difficult histories, often with cyclical patterns of being in and out of official 'care' settings or prisons. The following short comment illustrates this common pattern:

> I lost my mum when I was six and lost my dad when I was in prison. See I was 10 years in prison and came out and got a house. (Participant 3)

Participants graphically described their efforts to impose stability on their lives, although these were extensive, they frequently fail:

> That's why I am here now. I didn't want to go travelling around again; I've done that so I don't want to do that now. I need to be stable, like getting a flat or a house. (Participant 9)

and

> . . . I stayed with my mum for a good while. After they had made the house 'abandoned' I moved in with my partner. I stayed with my partner and then after I was out a couple of times on the streets sleeping rough on the streets, just basically where I could get my head down. (Participant 2)

Instability is a core feature of all the interviews and takes many forms. The roots of instability are generally difficult to trace from participant accounts although family disrupture and loss again feature prominently in this respect:

> Well I lost my mum when I was 6 year old and lost my father when I was in prison.

and

> My father got married again. I was in approved schools. (Participant 8)

Other interviews also indicate early family disrupture as contributing factors to chaotic lifestyles in adulthood:

> The first time I had a social worker was when I took an overdose when I was 14 and a half. I got ⟨man's name⟩ and another one, that was the first time I was ever involved with social workers. (Participant 5)

and

> My mum left when I was 14 and that's when I moved in with ⟨neighbor⟩, because she knew me. I practically stayed with her. Because it was my mother's boyfriend at the time that was being horrible to me. I took him to court. (Participant 10)

Self-neglect, abuse and hoarding

Previous studies only have commented infrequently on poverty. Generally, there has been an implied inverse relationship with many self-neglecters having professional backgrounds. Many participants in this study had experienced severe financial problems, some of which were caused by addiction to alcohol and other substances, but many of which appear to be part of a more general pattern of social exclusion. Difficulties negotiating a way through the contractual and form filling with banks, local government and other bodies were evident:

> Perhaps my job was my downfall. I was working for a security firm all over the shop, never around on rent days. I set up a direct debit but my bank screwed me about so changed bank and never changed direct debit. Megabucks of arrears. . . . I couldn't make the payments they wanted. I went and spoke to them. They reduced it a bit, so I make the reduced payments not that much of a reduction. Then after a while they sent me an eviction notice. (Participant 6)

Living conditions varied as a number of participants had been made homeless and were living in Salvation Army accommodation. For those still living in social housing the local social services had already begun to intervene and support participants to undertake actions to address hygiene in their homes. Squalor which was reported in a number of cases had by the time of data collection been successfully addressed, at least in the short term. This may be an artefact of the sampling strategy as local government agencies appeared very anxious to recruit 'success stories'. Payne & Gainey (2005) argue that differences in rates of self-neglect between different geographical locations can be explained by the possibility that there is a relationship between self-neglect and community characteristics.

Similarly, at least one participant highlighted that drugs were taken in a failed attempt to impose order on a chaotic social life and to appease social workers:

> I was taking speed before heroin so that I could keep up with all the housework because the social workers were on at me keeping the house. (Participant 5)

The complexity of self-neglect presentations which professionals need to work with was a common theme:

> Because I was self harming and drinking I was drinking Vodka and taking Valium, I was pill-popping. I had three at the time but I had the still born twins after

> ⟨boy⟩. (Homestart) That's a voluntary organisation where someone will come out and help you if you want to go shopping or help you do your ironing or wash the dishes. Well it got to a stage. After the Homestart worker my pal came in from across the road, she was on a methadone prescription, and she sold 10 ml and ⟨daughter⟩ drunk methadone, so it ended up – they ended up in care for a week. The kids were there for a week and I got them back on the Friday and the social workers helped me get like a kettle and cutlery and everything because I trashed the house when they took the children. (Participant 5)

It would be easy but oversimplistic to consider these accounts as merely indicative of drug dependency and ineffectual parenting. Underlying these accounts is a sense that statutory services fail such clients, instead of supporting, inspire fear and mistrust. When a crisis occurs statutory services may respond punitively, as the above comments demonstrate this frequently exacerbates the initial presenting problem.

The issue of homelessness was raised by several participants. There is a distinction between 'rooflessness' and statutory homelessness, and it is possible to have the latter status without the former, as some of our participants detail below (FEANTSA 2006):

> I roughed it for a week then moved into the ⟨name⟩ project run by ⟨charity⟩. (Participant 6)

Homelessness is listed as one of the signs of self-neglect by the National Centre on Elder Abuse in the USA, although seldom features in the UK definitions. We would suggest that homelessness be seen as a consequence of self-neglect rather than as a symptom, and therefore it should be included as part of the assessment and intervention process.

Previously Lauder *et al.* (2005) have highlighted the permeable boundaries between self-neglect, neglect and abuse:

> All these people are using my address, and every one of them is £8 a week rent added on to this house. Because they are using my address.
>
> I don't know how many people, I don't know who to phone, who to tell, that these people don't live here any more. And because the phone is on incoming calls now I don't know who to phone and tell. [our emphasis] (Participant 10)

There was an almost total absence of hoarding or syllogomania in this sample of people who self-neglect. Many did live in relatively squalid or at least very untidy situations but once again not as dramatic as situations found in stereotypical cases (Cooney & Hamid 1995). This is an artefact of sampling decisions taken in this study but does offer support to the claim that hoarding and squalor may be features of distinct subpopulations within those described as self-neglecting. The presence of hoarding or syllogomania may be one of the key conceptual and diagnostic issues in distinguishing between presentations of self-neglect.

Discussion

The picture painted by the participants in this study is one of uniformly extremely chaotic lifestyles. This was in some cases characterized by cycles of housing and homelessness. The level of chaos and disruption in their lifestyles appears to be more prominent than portrayed in the relatively static lifestyle of other, more severe, cases of self-neglect (Macmillan & Shaw 1966). Many studies of self-neglect do not include participants who are homeless and whose lives tend to be more chaotic and transient than more severe and established cases of self-neglect. This may be a dimension that needs to be more fully accommodated in both sampling in future research and in service delivery.

Distinctions drawn in this study between poor self-care, squalor and hoarding help to clarify a number of core questions in defining self-neglect. Self-neglect may usually, although not always, be accompanied by a varying degree of squalor. Self-neglect and squalor can exist in the absence of hoarding, and thus this analysis supports the Snowdon *et al.* (2007) distinction between self-neglect and hoarding. Montero-Odasso *et al.* (2005) suggests that collectionism is a helpful clue suggesting the presence of severe self-neglect, albeit this claim is based on single case study. The distinction made by Lahera *et al.* (2006) between collectionism, hoarding as part of an obsessive compulsive disorder presentation and hoarding as part of a self-neglect manifestation is useful, especially if supplemented by some element of decay in the material being hoarded. Self-neglect, neglect and abuse may be concepts which are clearly distinct in terms of definitions but which can coexist and interact in ways which are compounding.

Service refusal is frequently portrayed as essential part of self-neglect syndrome (Hurley *et al.* 2000). This study presents a somewhat different picture in which the structure, organization and attitudes of service agencies can become part of the problem. Participants were in contact with a range of services and appear to have greater acceptance and trust in voluntary services. Statutory services were often regarded with some degree of suspicion and frequently seen as agents of social control and surveillance, often removing children, houses and possessions when the participants needed those most. Charities, shelters and voluntary bodies (many from churches and religious groups) are prominent within participants' accounts and are respected by the participants who often use them as a service of last resort. In many respects, these voluntary bodies are the only available sources of help and support to people who self-neglect. Consequently, this problem should

not be seen as a feature of the self-neglecting individual but as an interaction between the individual, the organization offering the service and the utility of that service as seen from both perspectives.

The inevitable finger of interventionist institutions and 'care' agencies can be seen as a feature of many accounts. Abuse and social exclusion factors are prevalent, while homelessness (whether statutory or implicit) features heavily also. Nevertheless, participants were in contact with a range of services, and it was often the voluntary sectors which were perceived as providing services based on trust and which were responsive to needs of participants. Ill health, depression and disabling conditions were commonplace contributory factors with substance dependencies, particularly alcohol, also featuring heavily. In this respect, these cases are consistent with previous studies (Snowdon *et al.* 2007) and strengthen the argument for a subcategory of self-neglect associated with substance abuse. The coexistence of other conditions in self-neglect is well established, but the relationship to self-neglect remains unclear (Gibbons *et al.* 2006). Thus even in this younger age group comorbidity is still very prominent.

Many manifestations of self-neglect seen in this study are shared with the stereotypical self-neglect presentation. Consequently, these cases suggest that self-neglect viewed in terms of housing, squalor and poor self-care is more complex and contains a broader spectrum of presentations than the current literature suggests. This group differed from many existing studies of self-neglect in the extent to which individuals had a range of social contacts, unlike claims that all self-neglecters are anti-social and aloof. Self-neglect does not exist in a vacuum; it is part of a broader context and participants in this study had their self-neglect embedded in a range of problems associated with social exclusion.

Conclusion

This sample is a very different group than evident in previous studies (Macmillan & Shaw 1966, Cooney & Hamid 1995, Lauder *et al.* 2002), but they had been identified as self-neglecting and had many key features of self-neglect. Although they did differ in significant ways from stereotypical cases as anticipated, and this facilitated discussion on what is and is not self-neglect. This study builds on existing research (Halliday *et al.* 2000) which appears to reject the proposal that self-neglect is a geriatric syndrome. It may be the case because of its association with disorders such as dementia which are more prevalent in old age and the chronic nature of this phenomenon that it is more common in old age. Additionally, many studies specifically exclude younger participants (Abrams *et al.* 2002, Beauchet *et al.* 2002, Payne & Gainey 2005).

This study explored self-neglect from the standpoint of a group of people regarded as self-neglecting, but who differed in significant respects to stereotypical cases. Their lifestyle was similar to classic cases of self-neglect in some respects, but they differed in the extent to which they were younger, maintained social contacts and were in close contact with health, social or voluntary services. These related cases suggest that lifestyles and behaviours which we classify as self-neglect are wider and less clear-cut than previously suggested.

Comorbidity is an ever present feature of self-neglect in all its presentations, although this appears to be a much wider issue than the presence of mental illness. It may be that the specific type of comorbidity allows a typology of self-neglect to emerge which has practical heuristic value. For example, self-neglect coexisting with drug use in a younger person who has active social contacts has very different ramifications than self-neglect in an elderly person with dementia who has no social contacts.

Despite an increasing knowledge base on the extent of self-neglect on a UK and international level, it remains poorly understood (Lauder 2001). There are few evidence-based treatment guidelines or specifically developed interventions evident. In addition, only a handful of studies worldwide have attempted to understand the self-neglecter's perspective, how they view services and how these can be constructed to produce more user-friendly services. This is a notable limitation in service delivery given the fact that service refusal is almost pathognomic of severe self-neglect (Hurley *et al.* 2000). No single problem dominates the service delivery aspect of the literature more than the unwillingness of this client group to accept health or social services. Even in those relatively clear-cut cases of severe household squalor, there remains no 'gold standard' intervention, nor even consensus as to whether an intervention is needed in the first place.

Service refusal should not be seen as a feature of self-neglect *per se* but as a mismatch between needs of the self-neglecting person, and the ways in which services are structured and offered.

Study limitations

The findings of this study should not be generalized to the wider population. The study design was developed to explore theoretical and conceptual aspects of self-neglect. More specifically, this study was an attempt to map out some of the conceptual limitations and boundaries of current theory, and as such it was just as important to explore what was not self-neglect as it was to explore self-neglect *per se*.

In terms of biography, it is difficult to compare these biographies with others in the literature as they are almost totally absent from published literature. By selecting cases of younger people, it may be that we captured cases at an earlier stage in a self-neglecting trajectory or in fact these cases do not progress to severe self-neglect. This suggests the necessity for longitudinal studies to be conducted which would track the natural history of self-neglect in its many forms.

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