NURSING THEORY AND CONCEPT DEVELOPMENT OR ANALYSIS

Sociological and psychological theories of self-neglect

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Submitted for publication 12 March 2002
Accepted for publication 10 July 2002

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LAUDER W., ANDERSON I. & BARCLAY A. (2002) *Journal of Advanced Nursing* **40**(3), 331–338

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Background. Self-neglect can be defined as the failure to engage in those self-care actions necessary to maintain a socially acceptable standard of personal and household hygiene and/or a failure to adequately care for one's own health. It is generally acknowledged that research and practice in the area of self-neglect has been hampered by a lack of theoretical development. Socio-psychological theories, such as 'social constructivism' and 'negotiated interactionism' can contribute to a deeper understanding of the phenomenon and to the further development of self-neglect theory.

Aims. This paper seeks to apply social and psychological theories to understanding self-neglect. Self-neglect is an underconceptualized phenomenon, which requires to be studied within a broader theoretical context than is at present the case.

Implications. Sociological and psychological theories offer radically different ways of looking at self-neglect, as opposed to the medical model, as they seek to explain and understand, rather than simply classify it as a medical disorder caused by some form of underlying psychopathology. These theories emphasize the dynamic and interpretative nature of self-neglect and illustrate the arbitrary way in which this label is applied.

Keywords: self-neglect, squalor, social constructionism, deviance, labelling

Introduction

Severe self-neglect has been described as the failure to engage in activities that a given culture deems necessary to maintain a socially accepted standard of personal and household hygiene, and to carry out activities needed to maintain health status (Lauder *et al*. 2001). There appears to be a consensus that a proportion of cases of self-neglect can be explained by the presence of an underlying mental illness (Radeburg *et al*. 1987, Lauder 1999). Lauder has raised doubts as to the validity of labelling dementia sufferers as suffering from a self-neglect syndrome. Similarly the general use of medical diagnoses, such as the Diogenes Syndrome and Senile Self-Neglect, to explain the wide range of behaviours which come under the general rubric of self-neglect has likewise been criticized (Johnson & Adams 1996). Diogenes Syndrome is the medical diagnosis often applied in cases of severe self-neglect. This diagnostic label makes allusions to the proposed similarities between self-neglecters and Diogenes of Sinope, the Ancient Greek philosopher who demonstrated his rejection of material things by living in a barrel. He was known as 'the dog' in Greek, from which our word cynic derives.

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Laing's (1969) rejection of a wholly biomedical construction of disease was specifically aimed at mental illness. Laing argued that 'madness' was not an irrational disease state but an understandable and comprehensible response to a particular set of experiences. Whilst not necessarily supporting this claim as a general precept, it has currency in supporting a challenge to the number of seemingly pseudo-diagnoses, such as the Diogenes Syndrome (Cooney & Hamid 1995), which appears to medicalize many aspects of everyday behaviour and lifestyle. The dynamic nature of the concept of self-neglect and its application, in terms of medical diagnoses, to specific individuals has not been fully understood. Sociological and psychological theories may facilitate a better understanding of self-neglect and the dynamic processes through which it is constituted, rather than simply categorizing self-neglect in medical nomenclature.

It is important that theoretical perspectives other than the medical model are used to fully understand complex and nebulous behaviours like those ascribed to self-neglect. The value of using a range of theoretical perspectives to understand and investigate a phenomenon is put succinctly by Turner (1995) who states

> To regard illness as a text open to a variety of perspectives is a radical approach to sickness, because it points to some of the problems in the Medical Model…Modern medicine, treating the body as a sort of machine, regards illness and disease as malfunctions of the body's mechanics. (p. 206).

This paper seeks to take up the challenge, implied by Turner, by engaging in a discussion of the potential of sociological and psychological theories to offer a variety of additional ways in which to understand self-neglect. Expanding the theoretical perspectives available to researchers and practitioners will provide the necessary basis for a more rounded and responsive approach to treatment and research of self-neglect.

Sociological and psychological theories

Sociological and psychological theories of self-neglect put the spotlight on a number of fundamental questions such as 'what exactly is the nature of the problem?'; 'who has the problem?'; and 'who is best placed to respond to the problem?'. With regards the 'what is the problem?' question these theories offer a variety of perspectives at the social, cultural and individual level. Self-neglect understood within a socio-cultural context requires that we understand that judgements of self-neglect are rooted in contemporary values regarding hygiene and cleanliness (see Lauder *et al.* 2001 for a discussion of social judgements). At the individual level the voice of the self-neglecter has been sadly omitted from the diagnostic equation. Socio-psychological theories illustrate the necessity to broaden our understanding of the complexity of this phenomenon from its current wholly psychopathological stance to one that includes lay beliefs. What seems to be missing from the diagnostic equation is a genuine attempt to understand the world from the patient's perspective. This level of analysis is more complex than resorting to the usual admonishments to explore the patient's experience, which has become the usual frame of reference for much nursing care research. It involves exploring the ways in which experience is constituted and in turn constitutes the complex interplay of culture, social values, personal circumstances (past, present and anticipated) and nursing-medical practices.

The issue of who has the problem is at first glance looks absurd as it is obviously the 'patient with Diogenes Syndrome'. These theories challenge the idea that the problem is located within the individual and others, such as neighbours, are merely people who have been affected by the self-neglecter. Self-neglecters are frequently portrayed as individuals who do not believe they have a problem and wish to live the type of lifestyle which others object to. Many referrals to health care agencies and police seem to stem from neighbours complaints about the public health risk posed by self-neglecters. It may be the case therefore that self-neglect is a problem of people other than the self-neglecter.

Self-neglect may be understood differently by the range of professionals involved. For example, housing departments may understand this to be a problem of poor housing tenancy and of rent arrears, environmental health may see this as a problem of filthy and verminous tenants.

Sociological and psychological theories also force one to consider how individuals have come to be objectified as self-neglecters and whose interest this serves (Habermas 1971). It is worth considering the processes by which nursing and medical careers benefit from constituting the patient as an object of intellectual study. In effect, self-neglect and its various synonyms has become a valuable commodity in the academic market place. The claim of academics to have an objective and nonexploitative stance in relation to the phenomena they study is brought into question and the contrary claim can be made that they, in fact, gain from portraying self-neglect in a particular fashion. Sociological and psychological theories of self-neglect do not necessarily portray the self-neglecter as a passive diseased individual but as an active actor in the creation of this identity. This opens up the possibility that the self-neglecter may retain important coping mechanisms that can be utilized in thoughtful interventions. An all-or-nothing concept of self-neglect may not fully explain the way in which self-neglecters respond to

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their own, or those of significant others, self-care needs. Lauder (1999) reported a number of cases of self-neglect in which self-neglecters would care for significant others at their own expense, or in other cases would take care for some aspects of their life but neglect others. The theories to be discussed in the following sections are not exhaustive of the many potentially useful theories, but are perhaps an arbitrary selection chosen to illustrate the radically different ways in which we can understand self-neglect.

Social constructionism

Social constructionism is a theory that has had a relatively high profile in health and health care theory and research. Kendell (1991) summarizes the constructionist position by citing Rousseau's remark 'Il n'y a pas de maladie, il n'y a que des malades' (there are no illnesses, there are only sick people). Kendell assumes a constructionist position when proposing that psychiatric diagnoses, and by implication nursing diagnoses, are human constructions. The only questions that he thinks need to be addressed is whether diagnoses are useful? to whom and in what context? Rogers (1991) makes a similar point when arguing that, when we think of ourselves as being ill, we are engaging in a process of social definition. Illness is meaningful to the extent that it has specific implications for each individual. Social constructionism proposes that reality does not exist independently of perception and that furthermore the medical model has created its own objects of concern and its own version of reality (Armstrong 1994). Kendell (1991) contrasts 'diagnoses-orientated nursing' and medical practitioners who believe diagnoses exist *a priori*, with 'constructionists' who regard these diagnoses as human abstractions, justified only by their convenience and utility.

The notion of disease as a social construction has been used to understand a wide variety of phenomena, ranging from Drummond and Mason's (1990) research reporting how General Practitioners and patients (who had diabetes) operated different constructions of diabetes, through to Sontag's (1991) claim that Acquired Immune Deficiency Syndrome (AIDS) is a construction comprising of an open-ended list of presenting and contributing illnesses. Sontag describes how AIDS has come to be understood within the constraints of the metaphors of war, conflict and technology, which are commonly used to portray disease. AIDS has been portrayed as a war between good and evil, with which we must do battle using science age weapons.

The more general proposition that diseases can be constructed in very different ways is graphically illustrated using deafness as a case study (Gregory & Hartley 1991). Gregory and Hartley identified a number of very different constructions of deafness that have a direct impact on how deafness is understood in contemporary culture. The clinical psychological construction views deafness as a sensory impairment. Thus deafness is seen as the defining feature of a deaf person in contrast to the fact that hearing is not regarded as the defining feature of the hearing person. The medical model views deafness as a pathological state that must be conquered. This construction objectifies deafness by its reliance on audiometric measurement and the subsequent classification of deafness, which in children especially has a dramatic impact on their lives. The third construction is deafness as constructed from the deaf person's perspective. Deaf people are seen as a cultural minority who have had to construct their experience within a hearing world and framed by the language of the dominant discourse.

According to Turner (1995) constructions of disease are products of an historically and culturally located discourse. He gives the example of homosexuality which was regarded as a sin in Victorian religious-based conceptions of behaviour, a neurosis in early twentieth century medicine, and a sexual preference in contemporary medicine. A historical and culture-bound notion of cleanliness and hygiene highlights challenges to the idea of a universal category of human behaviour that is independent of the context in which it is described. A self-neglect syndrome was first formally proposed in the 1960s and one wonders if this syndrome would have existed in Victorian Britain or whether it exists in nonindustrialized countries today? This line of argument has underpinned a recent emergent critique in which the arbitrary nature and culture-bound nature of social and nursing-medical judgements of cleanliness and self-neglect have been exposed (Johnson & Adams 1996, Lauder 1999). This critique also rejects the idea of a single and fixed category of self-neglect which exists independent of cultural, subcultural and historical influences in favour of a number of fluid and shifting constructions of self-neglect.

Lupton (1994) outlines a number of criticisms which have been levelled at social constructionism, the most important of which is its relativist epistemology. The issue at dispute is, if we are to accept the relativist position that all constructions of self-neglect held by social actors are equally valid, how are the claims of each perspective to be judged? If the health and social care team believe an individual has a self-neglect syndrome and needs to be treated forcibly in hospital and the self-neglecter themselves believes they are living a lifestyle they wish to lead whose version of events is to be regarded as truthful? The answer to this question in specific cases has serious implications for the person identified as a self-neglecter who rejects the nursing-medical version of events, legitimized in the language of nursing-medical diagnoses, and

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then finds themselves dragged in to what must appear like a Kafkaesque world of medico-legal apparatus. This can involve forcible treatment, removal from their house and the so-called 'dirty squads' being called in to clean up the house (Shah 1995). Social constructionism does not explain fully why individuals reject social norms on hygiene and live a lifestyle very different from others, in spite of major social sanctions which they may, and often do, face. To understand the ways in which individuals understand and act in the social world requires that we view the self-neglecter as a unique individual as well as a social actor. This individual perspective, missing from social constructionism, is given a central role in Personal Construct Theory.

Personal construct theory

Personal Construct Theory (PCT) is a constructivist perspective which, unlike social constructionism, focuses on the ways in which individuals understand and construct their own experiences. It is a psychological theory that attempts to uncover the unique and sometimes idiosyncratic beliefs individuals have about themselves and their illnesses (Kelly 1955). The proposition that people construct their own ideas about the world and their experience of that world is the organizing principle of PCT. This theory operates on the assumption that people make sense of the world through a set cognitive schemata, which Kelly refers to as personal constructs. Self-neglecters frequently do not buy into the social consensus about hygiene, in fact not only do they reject it, they frequently do not believe that their lifestyle is unacceptable to many. Individuals can make a deliberate decision to not only live in circumstances which most would find abhorrent, but actually see this as a lifestyle of preference. Cases such as this require that we examine and attempt to understand the personal constructs of each individual self-neglecter. It is not possible, given the limited amount of empirical data, to say a great deal about this so far hidden feature of self-neglect. Very few studies have even considered the idea that self-neglecters themselves may have something to contribute to understanding this phenomenon.

Personal Construct Theory, unlike to social constructionism, does not offer a convincing account of how people collectively construct meanings of disease (Rogers 1991). It does not deal with social processes implicated in the various professional and lay constructions of self-neglect. The bipolarity of the theory does not describe adequately the complexity of human constructions of self-neglect. Rogers implies that a synthesis of PCT and social constructionism is necessary for a fuller account of self-neglect to emerge. This type of synthesis would assume that construction of self-neglect have an external as well as internal origin. Essentially it describes a mutually constituting process in which the external social world and the internal world of the individual interact with, and influence each other. Constructions of self-neglect are plural and that these are influenced by social and cultural values in conjunction with the idiosyncratic cognitive schemata of each social actor. Constructions of self-neglect are therefore placed in an historical context and attempt to describe the ways in which this context leads to the reification and subsequent dominance of any particular construction. The theoretical position to be considered in the next section offers up the proposition that disease, in this instance of self-neglect, may play a part of smooth social functioning.

Structuralist–functionalist theories

The basic premise of functionalism is that roles are necessary for the smooth functioning of social operations (Wolinsky 1988). Structuralist–functionalist perspectives draw on the biological notion of systems and anthropological notions of social structures and homeostasis of cultures (Gerhardt 1989). Parsons (1960), possibly the most well-known functionalist, proposed that roles and the capacity of individuals to fulfil these roles are important in understanding illness and disease. Wolinsky (1988) identifies the four aspects of the sick role as expectation of exemptions from normal obligations and of nonresponsibility, and obligations to get well as soon as possible and to seek competent medical help. Case reports of severe self-neglecters, which admittedly tend to portray a very selective picture, suggest that they do not meet social obligations to get well and seek help. This view dominates the medical literature and simply sustains and extends a particular constructions of self-neglect, a construction which serves the interests of medical and nursing academics and clinicians. A failure to meet obligations may explain the very judgmental way in which some cases self neglect may be described by practitioners and the frustration they report when faced with having to respond to such cases.

Freidson (1970) extends the sick role concept by asserting that issues of responsibility determine whether or not an individual is to be offered the privileges implicit in the role. Those held responsible for their condition cannot expect the same level of privilege as those held not responsible. If self-neglecters are judged responsible for leading a life of squalor, approbation may be directed towards them. The concepts of blame and responsibility are often used interchangeable and it may be difficult to recognize when the self-neglecters is held responsibility in an existential sense of being the author of events aaa(Sartre 1968), or when they are being blamed and seen as an antisocial person. Paradoxically, one possible benefit of the medicalization of self-neglect is that some individuals may be absolved of blame and as a consequence

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are less likely to find themselves caught up in a cycle of conflict with health and social care professionals.

Gerhardt (1989) suggests that Parsons equates health with normality and illness with deviance. Normality has been given a privileged place in professional constructions of chronic illness (Welland 1998). The diagnostic process in general (Armstrong 1994) and self-neglect diagnoses specifically also centred on the issue of normality (Lauder 2001). Gerhardt (1989) describes the underlying dynamic in the diagnostic process as the undercurrent of presumptive normality. Implicit in the notion of presumptive normality is a view that similarity rather than diversity applies to disease behaviour and that the veneer of certainty in nursing diagnostic and medical pathology textbooks does not reflect the complexity of real life. A sense of discontinuity exists between textbook definitions of self-neglect and how it actually presents to health and social care workers in the real world.

In the context of self-neglect, practitioners are faced with individuals who do not fulfil social expectations about self-care and may also exhibit what may be seen as very bizarre behaviours. Therefore, in terms of the sick role, a practitioner is obligated to judge and categorize these behaviours as abnormal. This provides what is essentially a value judgement with a measure of social validation and legitimacy in the form of a medical diagnosis. In contrast to the static view of the self-neglect role offered by structuralist approaches, the next section will explore how self-neglect is a label applied as part of a fluid and negotiated process.

Interactionist perspectives

Interactionist perspectives of disease and illness include both labelling and antipsychiatry theories (Gerhardt 1989). Here self-neglect is seen as a label of convenience applied by health and social care professionals. Disease and illness are seen as both biological and social realities, which are not fixed structural categories but are in fact fluid and dynamic. What is of interest is not the signs and symptoms of self-neglect but the way in which these are perceived and categorized. The interactionist perspectives moves from the Parsonian belief that medicine legitimizes self-neglect to the view that medicine actually defines it (Gerhardt 1989). In effect, what may be defined as a disease or syndrome is potentially limitless. Knowledge, which is used to put someone in a particular role with regards to issues of hygiene is the key to understanding an interactionist perspective on self-neglect. The constituting role played by language, iconography and professional journals in the production of a self-neglect syndrome has been described by Lauder (1999).

Habermas (1971) supports the distinction made earlier between work knowledge (empirico-rational) of self-neglect found in the academic literature with the practical knowledge of those involved with self-neglect as it appears in practice. Practical knowledge is governed by consensual norms which set up rules to guide reciprocal expectations about individual behaviour. The validity of such behaviours is made in terms of intersubjectivity of the mutual understanding on intentions of social actors. Habermas believes that hermeneutic-historical sciences, largely absent from self-neglect theorizing or research, are vital to fully understand practitioners and self-neglecters' constructions.

A variant of the interactionist perspective is negotiated interactionism (Gerhardt 1989). Gerhardt argues which negotiated interactionism proposes that deviant roles are not the consequence of fixed structural forces, one implication of which is to suggest that deviance is not simply imposed by others. The simplistic notion that self-neglect diagnoses are made by nursing and medical practitioners to a powerless patient is challenged by interactionism. The application of self-neglect diagnoses is a dynamic process of negotiation between individuals. Negotiated interactionism focuses on the ways in which labels come to be applied through a process of negotiation between different views, with professionals' views normally taking precedence. Schelling (1956) describes the negotiation of the deviant role:

> the subject includes both specific bargaining and the tacit kind in which adversaries watch and interpret each other's behaviour, each aware that his own actions are being interpreted and anticipated, each acting with a view to the expectation he creates…(p. 125).

The deviant self-neglecter is no longer to be seen as a passive actor but someone who actively participates in the creation of the deviant role. This active participation in the creation of the self-neglect role is in direct contrast to the Parsonian notion of structural stability explicit in the sick role (Gerhardt 1989). This theoretical perspective is a cognitive one in which professionals use schematized and procedural knowledge to translate the self-neglecter's idiomatic, ambiguous and unstructured explanations into the unambiguous language of the professional domain. Katon and Kleinman's (1981) transactional model stresses the role of the negotiation process between two divergent explanatory systems: the nursing-medical model and the patient-centred model. Ineffective clinical encounters are explained by communication problems between professional health care workers and self-neglecters. Communication problems result in a failure to arrive at a mutually acceptable understanding of the problem, its causes, course, prognosis and treatment. A breakdown in understanding sets up the conditions that have resulted in an

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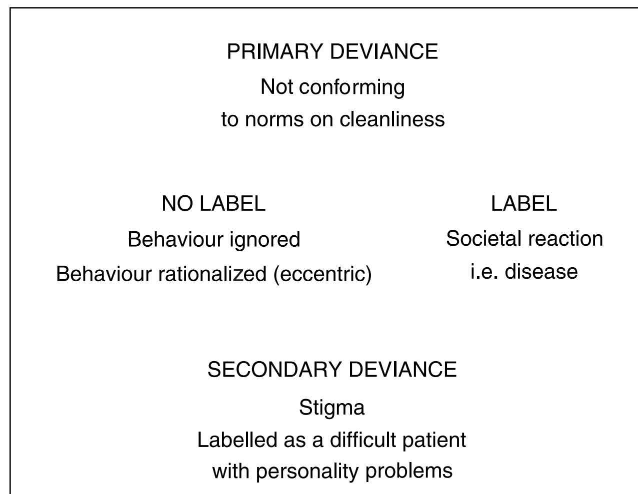

Figure 1 Labelling theory and self-neglect (adapted from Jones 1994, p. 408).

all pervasive sense of pessimism regarding professional responses to self-neglect. Interestingly this sense of therapeutic powerlessness is also characteristic of professional responses to childhood neglect (Daniel 1998).

The labelling perspective is another example of an interactionist theory (Scheff 1966). Lemert (1972), another advocate of labelling theory, believes that illness is one example of deviance and he makes a distinction between primary and secondary deviance. Primary deviance describes individuals who do not conform to social norms and secondary deviance occurs when primary deviance is labelled and the person becomes further stigmatized as a consequence (Figure 1). The deviant person (i.e. the self-neglecter) is then unconsciously committed to fulfilling the deviant role. The act of labelling self-neglect sets in motion a circular process in which the self-neglecter's response to the label becomes further evidence to support the original label.

Disagreements between lay and professional constructions of disease and illness has been addressed by Pilowsky (1978) and Turner (1995). Pilowsky (1978) advanced the concept of Abnormal Illness Behaviour, which he applies to patients who adopt an inappropriate way (according to a professional carer) of acting in relation to their health which is in direct opposition to the professional's view of how they should act. This is an important issue and is a common theme in the self-neglect literature in which frequent disagreements between professional carers and patients are reported.

Attribution theory

Attribution theory is different to the other theories discussed in this paper in that it does not provide a mid-range theory of self-neglect *per se* but provides an explanatory framework for a number of discrete features of self-neglect. Attribution theory (Kelly 1973) describes the way in which we infer traits and characteristics on the basis of another's behaviour. Jones and Davis (1965) suggest that we categorize people as having a particular trait or characteristic by selectively emphasizing and focusing on certain types of behaviour, especially those with low social desirability. In the context of self-neglect, mental health status may be overemphasized to the exclusion of other equally important factors when professionals make judgements about self-neglect (Lauder *et al.* 2001). Habermas explains how professional language is a strategic resource in the power relations between professional and lay constructions of self-neglect. Linguistic theory extends this position by explicating the process by which terms such as Personality Disorder and the 'Diogenes Syndrome' act as high modality markers. High modality markers give a text a sense of being scientifically based, credible and more important than text without such markers, as is usually the case when self-neglecters describe their own situation. One consequence is that the language used to classify self-neglect syndromes obfuscates the reality of self-neglect as experienced on the ground. In effect, self-neglect, as seen from the self-neglecter's position, is hidden from view or alternatively dismissed as a manifestation of mental illness.

Attribution theorists have identified a phenomenon they describe as the Fundamental Attribution Error (Ross 1977). This phenomenon describes a tendency of individuals to attribute behaviour to a disposition of another individual rather than to situational variables. This may explain the trend in the self-neglect literature that places emphasis on individual personality disorders as a causal mechanism for self-neglect at the expense of more complex mechanisms, which include contextual factors such as culture and social class. These views on the centrality of individual psychopathology in all cases of self-neglect are, and remain, deeply held within medicine and psychiatric nursing in spite of the lack of convincing evidence to support them (Lauder 1999).

Summary

We do not claim that self-neglect does not exist, that self-neglecters do not have real health and housing problems, or that there are no underlying physical–psychological causes in a proportion of cases. What is being suggested is that our capacity to understand, respond and research self-neglect is limited by too few theoretical perspectives. The theories briefly outlined in this paper attempt to bring other explanatory frameworks to bear on understanding self-neglect. Each theory contributes to understanding a particular aspect of

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self-neglect and the way in which it comes to be understood by different social actors. Socio-psychological theories highlight the influence of cultural values and history in the way in which we construct and respond to self-neglect.

The arbitrary nature and culture-bound nature of judgements of cleanliness and self-neglect have been articulated in a critique which has emerged from socio-psychological theory. This critique proposes that self-neglect is not a fixed and objective category of human behaviour but is in fact a product of a fluid and dynamic process of meaning giving. In this dynamic perspective the self-neglecter is not a passive actor but someone who participates actively in the creation of the deviant self-neglecter. The transactional model stresses the role of the negotiation process between two divergent explanatory systems which sets up possibilities for communication failures and general pessimism between professionals and self-neglecters about the success of any intervention.

What happens when patients, carers and professionals disagree as to whether the behaviour in question is self-neglecting or not? Research is needed to address the questions as to whether competing constructions accommodated in the therapeutic context or are a source of misunderstanding and conflict?

There is a dearth of studies evaluating current services which are made available to self-neglecters, in fact there is no clear understanding of the pattern of services which are made available in the first place. Constructionist theories of self-neglect have major implications at the policy level. In United States of America self-neglect is constructed as one category of abuse. In many states self-neglect is often defined within a legal context and is the statutory responsibility of the State Ombudsman. This is a very different approach to that observed in the Europe and Australia and is a direct consequence of the way in which the problem is understood and consequently is a good illustration of the way in which policy and theory are interrelated. The role of language and the iconography of self-neglect in constructing professional and lay beliefs about cleanliness and hygiene and the impact these beliefs have on labelling self-neglect is an area of potential research. This type of study would use genre analysis or discourse analysis methods, which should transcend various academic disciplines such as nursing, literary studies, film and media studies and English language studies.

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