

CARING FOR PEOPLE LIVING IN DOMESTIC SQUALOR

Introduction

District Nurses care for people in their home environment and see many different people living in diverse ways. Some homes that nurses enter raise concern because of the squalid conditions in which the client lives. This client group represents a small but resource intensive population for the Royal District Nursing Service (RDNS) of SA Inc. The nursing literature offers little about the ways nurses care for this challenging client group. The focus of this newsletter is to report the findings of pilot research undertaken with RDNS nurses, who had experience in caring for people living in domestic squalor.

What is the issue?

Domestic squalor has been previously defined as a home environment that is unhygienic and unsanitary due to the presence of vermin, and/or decomposing matter, and/or excrement. Effective health outcomes are difficult to achieve in such environments and managing care that is collaborative, ethical and just, is a concern of the RDNS. A recent literature review that discussed various cases (1100 people in total) of people living in squalor, revealed that more than half were older people¹. Given the propensity for older people to slide into squalid living conditions, it is useful to understand the assessment and ethical clinical decision-making processes nurses use in care, and the organisational processes that help to deliver quality care to people living in squalor.

What are the reasons for people living in domestic squalor?

Clients living in squalor may have health conditions such as dementia, alcoholism, schizophrenia and/or personality disorders^{1,2} and obsessive compulsive disorder^{3,4}. There is a syndrome called Diogenes Syndrome, which is a constellation of personality characteristics such as an urge to save items, avoidance of discarding, indecision, perfectionism, procrastination, disorganisation of possessions and activities⁵. Particular to Diogenes Syndrome is the hoarding of items that could be considered by others to be rubbish, with the person also neglecting self-care^{6,7,8,9}. Other causes of hoarding behaviour that may become squalor include alcohol and other drug addictions^{10,11}, intellectual disability¹², autism, attention deficit hyperactivity disorder^{13,14}, physical disabilities and chronic conditions that overwhelm the person or cause cognitive impairment^{15,16,17,18,19,20} as well as a number of mental illnesses such as obsessive compulsive disorder^{21,3,22,23,24,25,26,27,28,29}, schizophrenia^{27,30}, eating disorders³¹, depression and significant grief

reactions³², and personality disorders. Prader-Willi Syndrome also predisposes people to compulsive hoarding^{4,33}. Compulsive hoarding may also be familial as researchers have located genetic markers that may be associated with hoarding behaviour^{3,24,34}.

How was the research conducted?

The research aimed to understand the assessment and decision-making processes that RDNS nurses' use to provide effective care to people who live in domestic squalor. A qualitative design was used that included a literature review and semi-structured interviews with nurses. Ethics approval was obtained.

Twenty nurses that were employed with RDNS for more than five years participated. Seven nurses had worked in the role for more than 15 years. Most nurses' worked clinical rounds in the community, but four specialist nurses participated from mental health, infection control, strategic planning and management. Nurses were interviewed in 2007. Questions were asked about nurses experiences of caring for this client group, how they assessed the situation, and the assessment processes and intervention strategies employed to provide care.

The same experienced researcher interviewed all participants to ensure consistency. Each nurse's experiences built a picture of the issues, impacts, challenges and strategies used to care for this population. Interviews were audio taped, transcribed and analysed thematically to identify key themes.

What were the findings?

District Nurses describe squalor

Nurses were asked, what are the differences between hoarded clutter and squalor? There is no single 'squalor situation' so nurses develop individualised responses to each person's situation that were underpinned by professional knowledge regarding presenting health issues, possible interventions and probable outcomes; their life experience; and above all their personal and professional ethics. Nurses need to work cooperatively with the client to maximise the opportunities for quality outcomes within appropriate time frames. A nurse said:

We are trying to provide good care in an environment that is not conducive to quality outcomes. We cannot dictate to anyone how they must live and we need their cooperation in the care plan, but it is difficult when more often than not the client doesn't see their living conditions as unhealthy or uncomfortable. Most people know that they live in a hoarding environment, but they are content that way. Personally I don't worry at all about junk and clutter. In fact once you have experienced a few worse case scenarios of squalor, hoarding cases are nothing! The problems occur when you can see that the squalid environment is delaying wound healing and creating a lot of extra resource allocation for less than optimal results.

There was consensus that the hoarding moved beyond 'collecting' when it encroached on the person's capacity to undertake day-to-day functioning within their home. There were cases when hoarding created potential hazards for both the individual and the nurse. People hoarded newspapers, magazines, videos, paper and cardboard, containers, bottles, milk cartons, food, and rubbish. Animal hoarding often involved cats but also included dogs and poultry. Animal hoarders moved into squalor quickly because they could not manage the accumulation of animal faecal matter.

Nurses said that an environment became squalid when the hoarded matter included decaying organic filth, vermin, human/animal excrement; or unsanitary conditions had developed due to the build up of filth. One nurse said: *It becomes a problem for me when I cannot kneel down for fear of filth, damp and mould and microbes transferring on to me that I may in turn transfer to another client or to myself. The environment became unhygienic because she (client) kept every container from meals on wheels and originally they were clean, even though they were everywhere. Later, the food scraps were left in them and began to degrade and this decomposing matter present in the house was the time that hoarding became squalor.*

The Impact of Squalid Conditions on Care Giving

Nurses told of the physical challenges of caring for this population such as safety issues and injury hazards. Examples provided by the District Nurses include rotting floors; unsafe wiring; hazardous ceilings; spitting and hissing cats; vicious dogs; snakes; limited place to walk, stand or undertake sterile procedures; no place for hygienic food preparation; lack of access to bathrooms etc. There were also socio-cultural and personality barriers to healthy outcomes that include language and communication difficulties; abrasive, narcissistic personalities; relationships characterised by mistrust and suspicion, angry and violent outbursts.

Often these clients were difficult to engage and many had long-standing health and social needs. Older people often had co-morbid health conditions: *I went to see an 80 year old lady who we had cared for over many years. She was always a bit eccentric, choosing to live with disordered clutter, but now she had deteriorated to the point that she was not coping in her own home and it was fast becoming a health risk. She had dementia and insulin dependent diabetes. It was the middle of summer and she had forgotten to pay her electricity bill. I saw her on the Friday and returned on the Tuesday and her power had been cut off for those days. She decided to leave the fridge open to let air circulate around the food. When I arrived there were wall to wall maggots through the fridge and the smell of rotting food was disgusting. From that time we began the process of trying to get her placed. It took nine months to get her into care.*

Clearly, nurses experience the personal impact of caring for clients living in squalor. What nurses witnessed stayed with them long after the client was discharged.

Indicators of Squalor observed by District Nurses

Nurses were asked what indicators they found when they determined an environment was squalid and these are listed in Table 1 (see attachment). There will always be exceptions to these indicators, but they are based on nurses' clinical experiences.

District Nurses' assessment of clients living in squalor

When assessing clients living in squalid environments

nurses aim to be sensitive and suspend their personal values and judgments: *You try to blinker the mess. You cannot go in like a bull at a gate. You take bites of information until you get a good clear picture of what's happening. You remain calm and collected.*

Nurses are aware that their assessments are subjective and based on life experiences, lifestyle, cultural values and professional knowledge. They are cognisant of the impact that their actions have on clients and all the nurses interviewed went to great lengths to bracket personal judgement. Nurses prioritise relationship building during early contact with the client: *I am interested in primary health care and family dynamics, so I get to know the person's life story. I am interested in this and over the years I have learned the knack of getting a client's story. I listen and get the story in bits and pieces, seldom all at once. I invite them with something like "You are not just the person in front of me and it will help me to understand you, and be of better assistance to you, if I know a bit more about you. Can you tell me a bit about yourself?" These stories never go in the notes. They do not go on paper. The stories are treated with utmost confidence and respect and focused listening. I put my pen away and I listen. That's when people will talk to you. I am then better equipped with how to proceed to help and have more idea on how the person came to be like this.*

Early Assessment

Nurses ask themselves are 'Is this environment safe for me and for the client? Is it a problem? If so, whose problem is it? Whose needs am I being asked to meet?' 'Can I do what I know I have to do without harming myself or the client?' If not, then the nurse is obliged to tell the client that it's not possible to have a good outcome in the current home environment. Nurses then make alternative suggestions as to where and how to provide the required care. The nurse seldom discusses this with the client at the first visit. Rather, the nurse seeks the expertise of others within the organisation and they collaboratively plan how to proceed with care. During the first visit a quick clinical précis is made about competence and the possible need for guardianship in case the person has lost capacity. The nurses' priority is always to the client, then the client's significant others and the community, and lastly the authorities.

Nurses use observational and sensory information such as smells, sights, sounds. One nurse said, 'You go in like a vacuum cleaner and suck up all the information. If there's something important you do something about it... otherwise you store it and develop a picture over time.' Nurses try to 'understand the person's life story' and that needs to occur over time through social conversations. When nurses are looking at the house they note changes between visits, all the time checking the client's and their own safety, observing changes in the context that may indicate alterations in the client's health. The nurse listens carefully to what the client is saying while taking in information via conversation and observation. These comments illustrate: *I do a 'pan and scan'. I start by looking at where this client is now. I try to work out how I can get to the client (emotionally). I then work out a safe path to reach them and engage them in conversation to find out what's being hoarded and if there is a reason why there is collection like this. If the client gets defensive then I stop and don't go further at this time. However, I can try and talk to the family and/or other workers, because I will need some numbers on my side if I am to get a commitment to assist or intervene.*

I take a lot of mental snap shots as I scan the environment. I use all my senses, noting if the client is undertaking personal hygiene e.g. length of toe nails, where they sleep, if there is running water, what food they have and its status, what the wet areas are like, where any medication is stored, what risk the space or lack of space represents...

Developing the trust of the client was always important. Nurses said that they would not question the client's living conditions during the first visit unless the situation posed an immediate threat. Nurses choose their communication strategies carefully, kindly and assertively, explaining the situation when the time was right. Nurses ascertain if any action has been taken about the situation in the past. Further assessments are engaged to see if the nurse can locate a source of the problem, such as general physical or cognitive impairment, emotional problems, dementia or some other frontal lobe involvement or any other underlying problems.

Risk Assessment

When asked about the decision to undertake a risk assessment, one nurse said, *'The question you ask is, "Does the environment make any difference to the way I can provide care and the possible outcomes?" If not, then it is not a problem because there is no risk.'* If the conditions are particularly squalid then the nurse undertakes a risk assessment and compiles an occurrence notification and that commences a documented record that enables audit so people can check to see if the situation is worsening. Nurses raise a hazard alert by lodging an incident form so other staff can take note before they enter the client's premises. Nurses found the use of a risk tool and the organisational processes in place to raise alerts was helpful. The tool is aimed to reflect the overall goals and outcomes of the organisation while identifying and quantifying risks, recommending strategies and prioritising necessary interventions. The tool can constitute a specific risk management component of a client's file that is reviewed, as often as weekly in high risk situations. The risk assessment asks the nurse to:

- differentiate risk to staff/others and risk to client
- identify risk of harm to self, others and possibility of harmful outcomes
- determine the extent to which the risk effects functioning
- identify possible risks compared with the consequence of the most restrictive options
- identify the risk to everyone involved with the client
- determine the client's attitude to the situation and toward service providers
- understand the consequences of living with the identified risks;
- and level of support for the client.

A senior infection control nurse noted that District Nurses are well equipped to provide quality care in unhygienic environments. They are encouraged to use a variety of products such as alcohol gel, protective clothing and gloves. If nurses use standard precautions and appropriate equipment effectively, they can reduce risks. Wherever possible, nurses try to put the client living in squalor at the end of the daily round, but this is not always possible. Problems can arise when nurses do not routinely use the equipment, such as gowns and goggles, in the community setting. When asked why they choose not to wear protective clothing, the nurses are motivated by sensitivity and the desire not to offend or scare the client. A nurse commented, *"...you look like someone in the movies about to deal with an alien and*

the last thing you want the client to do, is to think that you are judging them, or their home environment, or for them to be afraid of you."

Risks for nurses can be high because of exposure to decaying matter and human excrement. It is important that where possible, nurses plan ahead and know the environmental risks posed. This will enable them to carry appropriate equipment. It can be difficult when the referral comes from a hospital where the referee is uncertain of the home context. RDNS provides equipment that will assist in reducing risk of cross infection and it is available to staff with instruction on when and how to use the equipment correctly. The nurse must then assume responsibility to use it.

Assessing Capacity

Nurses said that it is false thinking to assume clients living in squalor do not have intellectual capacity. There were occasions when a client's capacity or competence is in question. Assessment of the person's capacity to make informed decisions was a major. If the person has reduced capacity the intervention strategies able to be employed alter. Assessing cognitive capacity was often complex. One specialist nurse said that nurses may assume competence when client's complied or agreed with them, however cognitive capacity should always be assessed.

Nurses built a composite picture of the client's situation over time. Dyer et al (2007) found that over half of 460 persons aged over 65 years who were considered to be self-neglecting had abnormal 'Mini Mental State' scores. Consequently, it could be worthwhile to consider assessment of cognition early in the assessment process. Some nurses however, felt these tools were unhelpful concerning ethical care and early in the assessment process they prioritised the establishment of client rapport over data collection.

Choosing whether to intervene

Quality health outcomes in this client group were seldom achieved quickly. An approach by other services can be to hospitalise the client and then enlist industrial cleaners to dispose of the house contents and clean up. This approach increased client distress and exacerbated behavioural challenges when the client returned home. The decision to intervene was guided by principles of respect, autonomy and upholding human rights. Nurses would act to change the client's environment if they considered this was in the client's interest:

A person's living conditions is a personal choice. (District Nurses) are not there to change that, unless it is really compromising their health. Only then can we do something and it must be done carefully and respectfully. We are there for the person. If we want to create big changes in their environment then the best way to do that is to create many small changes over time. The client needs to agree to them and they will if our relationship with the person is built on trust, then they will trust us enough to believe that we want the best for them. It's not about what we think is okay to live in, it's about what is going to help this person and if it is just clutter that is OK, but if it's a breeding ground for vermin and microbes then it may be time to do some small things.

Enlisting cooperation

Nurses requested cooperation from the client as the first point in the intervention process. Nurses' actions were mediated by a desire to obtain positive health outcomes while maintaining client respect and autonomy. Most clients declined offers for assistance in cleaning, so

when cleanup was required the nurse needed the support of other team members and services. Collaboration with medical staff was important because there was little action that could be taken until the client's cognitive capacity was established. This population did not always see their doctor regularly, even though most had chronic health conditions. Often the GP may be unaware of the home situation. A rigorous client assessment was undertaken, preferably within the home and over time so the multifaceted factors that made up the situation could be captured. These findings were considered, alongside a range of statutory obligations such as occupational health and safety legislation, privacy legislation, environmental health legislation, tenancy agreements, and guardianship and detention orders. The approach of nurses remained person-centred: *Put the squalor aside for a moment, I always ask myself 'How am I going to deal with this behaviour, this situation, to get the best possible outcome and open the door to address the squalid living conditions at a later time?'. If you have not had this experience before, you can get the advice from others. It's useful to have the support of more experienced District Nurses who have successfully dealt with such situations before. The specialist nurses can be called upon to assist so you get the best care in what is clearly a compromised situation.*

Using a strength-based approach

It was important to approach the situation using a strength-based approach that harnessed the client, carer and community's strengths for that person. Nurses asked themselves 'What is the reason for the planned intervention? What is the goal?' Nurses said they would opt for the least intrusive form of intervention with the best probable outcome.

If the client had capacity, then nurses tried to persuade them to accept help. If this was unsuccessful and the environment had to be cleaned up, referrals were made to the Department of Health, or the landlord if the property was a public rental property. If the property was a private rental then referrals were made to local council environmental health officers who assessed the risk to the client, the neighbours and the community. They might involve the fire brigade, animal welfare organisations, and police, who could use appropriate legislation to determine property ownership and compel the client to clean up and remove the risks. When a client did not have capacity, a guardian was notified about the state of the accommodation. The guardian would be advised that decisions were required regarding cleaning and health interventions. The guardian could appoint a financial manager, who would arrange payment for industrial cleaning services. The Mental Health Act could be invoked to compel treatment access if necessary. Nurses said that for clients where there was a risk of violence, they would consider police involvement.

Discussing the state of the environment with the client

Nurses emphasised the importance of remaining person-centred and safety and outcomes focused: *The client was a woman with serious diabetes and other mental health needs. She had numerous cats and kitty litter that was never emptied. She ate from tins and there was rotting food all over the floor mingled with mountains of clothing, junk mail and other people's belongings everywhere. We could not even pick up paper without her having a serious outburst. You have to accept that this is how people choose to live. It's not fantastic for health care provision but it is their choice. However, the situation was going to affect health outcomes so action needed to be taken. We approached the topic by saying it was fine for her to live like this but we needed to have a safe environment for the nursing staff so could we clean up a small space for our staff to work in. She was able to accommodate this. We then began to work on establishing rapport, which needed a number of visits, before broaching the subject of an environmental cleanup. After a few visits I asked the woman 'What services are you receiving and what are they doing for you when they are here? Are you happy with these living arrangements?' I was able to ring other services to know what other agencies were doing or if they were doing anything. We then asked permission to bring in other services and when this was received we were able to proceed to negotiate a clean up of the living area and wet areas.*

Organisational processes that assist care

Nurses said that a system of hazard alerts and effective risk management systems, where self-responsibility was integral to the process, was an important organisational structure to support their care. They appreciated the formal alerts in a simple system that identified issues, documented them and talked about the problems within teams, so the planned approach was thought-through and understood by all personnel involved in the client's care. They appreciated the assistance of experienced staff who had a solid understanding of multi-service and interagency protocols, an awareness of clinical, social and domiciliary support services, and the ability to obtain and maintain entry into such services, while providing appropriate client and staff support. Nurses felt the success of RDNS was assisted by nursing practice that was under-pinned by primary health care principles and values. This assisted nurses in maintaining a person-centred approach that reflected their values of social justice, equity and sustainable practice.

Conclusions

The challenging clinical environment and client profile of self-neglecting and/or hoarding clients present many challenges. RDNS nurses, however, are providing person-centred care to clients living in squalor. Nurses aim to work carefully, sensitively and thoughtfully with these clients. The nurses' capacity to provide care can be hampered by living conditions that are not conducive to healthy outcomes. Assessing cognitive capacity for clients that are notoriously uncooperative is challenging. Nurses assess clients living in squalor by building a composite picture over time, using observation and multi-sensory information gathering skills, coupled with careful and focused questioning once rapport has been established.