

Meeting the health needs of older people with intellectual disabilities: exploring the experiences of residential social care staff

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What is known about this topic

- The population of older people with intellectual disabilities is increasing.
- Premature ageing may occur and multiple morbidities are common.
- Their day-to-day support may be provided by residential social care staff who are not required to have previous experience/knowledge regarding health needs.

What this paper adds

- Residential social care staff undertake a key role in monitoring the health of older people with intellectual disabilities and in addressing changing healthcare needs.
- They have a key role to play in advocating for those they support in the context of healthcare.
- The role of social care staff is not always well understood by those working in healthcare.

Abstract

Older people with intellectual disabilities often experience high levels of health needs and multiple morbidities but they may be supported by residential care staff with little or no previous experience of identifying and meeting health needs. Little is known regarding how they undertake this health-related role and this exploratory study seeks to address this gap. A purposive sample of 14 managers of supported living accommodation in Wales were interviewed in 2014 to determine their experiences of supporting tenants in relation to age-related health needs. The semi-structured interviews were transcribed and thematically analysed. Three of the emerging themes are reported in this paper: meeting health needs, the consequences of ageing and relationships. Findings indicate that residential care staff support older people with intellectual disabilities with complex and multiple health needs: they monitor health status, support access to healthcare, provide additional support arising from changing health needs and advocate for tenants in the context of healthcare. However, their role is often not understood by healthcare professionals. The importance of staff having a long-term relationship with those they support was identified as being important to identifying any health-related changes. The need to develop effective relationships with healthcare staff was also noted. It is concluded that there is a need for better understanding among health staff of the role of residential social care workers and for further research regarding health-related communication.

Keywords: ageing, health needs, intellectual disabilities, social care

Introduction

There is international evidence that people with intellectual disabilities experience inequalities or disparities in health status compared with the wider population (Emerson *et al.* 2011, Anderson *et al.* 2013, Krahn & Fox 2014): such inequalities impact on both quality of life and life expectancy. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) (Heslop *et al.* 2013) found that 42% of the deaths reviewed were considered to be premature, and that men with intellectual disabilities died on average 13 years earlier than their non-disabled peers, while women died on average 20 years earlier compared to non-disabled women. Common factors identified as contributing to this situation include delays or problems with diagnosis and/or treatment, and providing appropriate care as needs change (Heslop *et al.* 2013).

Nonetheless, the life expectancy of people with intellectual disabilities is increasing in Western countries and the number of older people with

intellectual disabilities is rising (Haveman *et al.* 2011). This population is ageing with a legacy of lifelong disability-related health inequalities while also being vulnerable to the age-related health problems commonly experienced by wider society (Krahn & Fox 2014). The need to promote healthy ageing among this population is recognised (World Health Organisation 2001) and healthy lifestyles including good nutrition, exercise and increased surveillance of health risks are viewed as ways of achieving this (Haveman *et al.* 2010). However, sedentary lifestyles (Haveman *et al.* 2011), higher rates of obesity compared to the wider population (De Winter *et al.* 2012), and under-diagnosis and poor management of treatable conditions are reported (Haveman *et al.* 2011).

The emerging population of older people with intellectual disabilities commonly face a range of age-related health issues such as cataracts, hearing loss, diabetes, hypertension, osteoarthritis/arthritis and osteoporosis (Haveman *et al.* 2011). Such conditions often occur in combination and individuals live with the combined effects of multiple chronic health conditions. For example, in their study of 1047 participants with intellectual disabilities aged 50 or over, Hermans and Evenhuis (2014) found that 79.8% had two or more such conditions and 46.8% had four or more. Elsewhere Schoufor *et al.* (2013) found that people with intellectual disabilities aged over 50 had levels of frailty comparable to those in the wider population aged over 75. This premature ageing is attributed to the impact of pre-existing conditions (e.g. specific syndromes giving rise to intellectual disabilities such as Down syndrome, long-standing sensory or mobility problems, epilepsy or other neurological conditions), level of intellectual disability, lifestyle factors, the metabolic effects of anti-psychotic medication and the reactive nature of medical care for people with intellectual disabilities (Hermans & Evenhuis 2014).

Many older people with intellectual disabilities reside in group homes/supported living settings where they may be reliant upon social care support staff to promote optimum health, to manage long-term (sometimes complex) health issues, and to enable access to health services when health deteriorates and interventions are required. However, concerns have been raised regarding the preparedness of staff within such settings to respond to the growing number of older people with intellectual disabilities (McGhee & Dorsett 2011). Whether older people with intellectual disabilities can be supported to 'age in place' rather than moving into nursing home care is discussed in the literature (e.g. Wilkinson *et al.* 2005, Webber *et al.* 2010a, Innes *et al.* 2012) and challenges have been noted in relation to providing end-of-life

care (Anderson *et al.* 2013), despite a willingness on the part of many staff to do so (Wilkinson *et al.* 2005).

Heslop *et al.* (2013) reported that problems with co-ordination between and across services contributed to premature deaths among people with intellectual disabilities. While that study focused on people with intellectual disabilities across the lifespan, such issues may disproportionately affect older people as they are more likely to be reliant upon paid care provided within the social rather than healthcare sector. Indeed, enabling older people living in supported living settings to access appropriate and timely healthcare involves working across a number of different organisational and service boundaries; between health and social care, between primary and secondary health services, between specialist intellectual disability services and generic health services, and between specialist intellectual disability services and services for older people. However, CIPOLD found that while paid carers reported advocating for those they support, health professionals did not always recognise their role or respect their views (Heslop *et al.* 2013). Indeed, while residential care staff play an important role in meeting the health needs of those they support, this is not always formally recognised as part of their role (Crimes 2014). Little is known about how such staff respond to age-related health changes among those they support (Webber *et al.* 2010a) and this study seeks to begin to address this gap in knowledge.

Context of study

This study focuses on staff working within supported living settings in Wales. Within such settings people with intellectual disabilities are tenants and third-sector social care organisations are contracted to meet their day-to-day support needs. Arrangements vary from sessional to 24-hour support (sometimes with waking night staff) depending on the needs of tenants. Typically, house managers oversee one or more houses and have responsibility for managing the staff team in order to promote person-centred care and support. Each tenant has an individual care plan developed by the staff team in collaboration with the individual, their family and other professionals as appropriate. While approaches to record keeping vary from organisation to organisation, all have some form of individual case file in which key issues (including those relating to their health) are recorded. As the managers are not present within the houses at all times, support workers are expected to contribute to maintaining these records. Staff are

employed within the social care sector, are not required to have any prior experience of supporting people in relation to their health needs and the requirement to provide such support may not be specified in their job descriptions (Crimes 2014). In addition to the staff team within the individual houses, tenants and staff are supported when required by a range of other professionals including members of the primary healthcare team, specialist intellectual disability staff (such as nurses and psychologists) and social workers/case managers.

Methods

Participants

A purposive sample of 14 house managers was obtained from five-third-sector organisations providing supported living services to people with intellectual disabilities in Wales, UK.

Of the 14 managers participating in this study, 11 were female and 3 were male. Only one participant had been in their current post for less than 1 year with eight having been in post 5 years or more. They were all involved in managing the support for tenants aged 50 or over with 13 of them supporting tenants aged 60 or over and 6 supporting tenants aged 70 or over.

Data collection

Data were gathered via semi-structured interviews undertaken during 2014. These interviews were, with the permission of participants, recorded for later transcription. The mean length of interview was 53 minutes with the range being from 30 to 82 minutes.

Data analysis

All interviews were fully transcribed and reviewed by RN with a selection also being reviewed by DHH and RJ. The research team then met to discuss and agree themes that were emerging from the data and from these developed an agreed framework for coding that included both the named themes and associated descriptors. The transcripts were subsequently entered into NVivo version 10 and coded thematically using this framework. A further selection of coded transcripts was then independently reviewed by RJ to promote rigour and final coding was agreed.

From this qualitative, exploratory stage of the study, five major themes emerged namely residential support staff prior training and experience, training about ageing and health, meeting health needs, the

Table 1 Overview of themes and sub-themes

Sub themes	Themes
Range of health needs encountered Recognising, monitoring and meeting health needs Health checks Accessing healthcare Record keeping Medication Specialist support	Meeting health needs
Signs of ageing Ageing in place The need for environmental adaptations End-of-life care	The consequences of ageing
Knowing the person Boundaries Relationships with health professionals	Relationships

consequences of ageing and relationships. To allow greater depth of discussion, only the latter three themes are discussed in this paper and they, and their associated sub themes, are set out in Table 1. The other themes are reported elsewhere (Northway *et al.* 2016).

Ethical issues

Ethics approval for this study was granted by the Faculty of Life Sciences and Education at the University of South Wales Ethics Committee. All potential participants were provided with an information sheet outlining the study and the voluntary nature of participation, and given the opportunity to seek clarification regarding any issue. Those agreeing to take part were asked to sign a consent form before interviews commenced. To promote anonymity and confidentiality, each organisation was assigned a letter and each participant a number: this is reflected in the attribution of participant quotes below.

Findings

The three themes that form the focus of this paper are discussed individually below with the associated sub-themes being identified in the text by the use of bold italic font.

Meeting health needs

Participants reported that there were a *range of health needs encountered* within their work. As might be expected when supporting older people with

intellectual disabilities, the most frequently reported conditions were epilepsy, diabetes, infections, dementia and other mental health issues. Other age-related health problems reported included cardiac problems, sensory loss and reduced mobility (in some instances requiring the use of a wheelchair). These health needs had, in some instances, given rise to the need for specific interventions such as catheter management, specific diets and enteral feeding. The interaction of multiple health issues was commented upon:

The main problems we have are chest infections and the trouble then is because all the service users who are wheelchair users, for all of them have eating and drinking problems as well, So the risk then is that they could aspirate. (D2)

It was evident that residential care workers are involved in *recognising, monitoring and meeting health needs*. Included within these activities was an attempt to promote healthy lifestyles wherever possible:

Yes we all work towards healthy lifestyles. One of the service users has gallstones so they follow a healthy diet with that. Another one has got cholesterol they have been given the relevant diet sheets and sit and support the service users to do their menu for the week... (C2)

In some instances, participants commented on how staff had identified changes in health needs among tenants and had sought to determine the cause of these:

So as we introduced things she went to the GP, went for a hearing test, she went for an eye test, dentist, all the things where we thought she could be in pain. (E3)

In other instances, regular monitoring was being undertaken to determine whether any changes were occurring:

I mean one of the guys now they are starting baseline assessments which is interesting because what they are saying is we are looking to the future. (A2)

An important element of monitoring tenants' health needs noted by the majority of participants ($n = 10$) was supporting them to have their annual *health check* via their local primary care team. Generally, the experience of such checks was reported as being positive and, in one instance, the GP even came to the house where it was difficult for tenants to attend the surgery. However, elsewhere challenges were experienced and staff had to advocate for their tenants:

Yes they have their OK health check every year which is a full physical. That is done by the GP, we did have trouble

setting them up but I think the GPs have got that we are not going to go away. We keep coming back. (C1)

These differing responses from healthcare providers were also reported in relation to other aspects of *accessing healthcare*. Some reported very positive experiences:

I find ... they are very understanding in dealing with the ladies ... with the GPs surgery what I find is that then we say we have a problem with the ladies getting up to the surgery the GPs were happy to come out and always on the end of the phone, really being supportive in that way. (E1)

However, not all experiences were so positive and difficulties were reported with both primary and secondary care:

...he had one GP who had happened to come out two or three times in a year, that was all it was for little things. He actually wrote this letter and said that if called out again to see this certain gentleman, he will have him sectioned,¹ because if he cannot come to the surgery and he cannot do this then why is he in the community. (C5)

When you attend appointments then in a hospital, especially if they have got emergency appointments, then it can be difficult because I don't think the training is there for people to be able to work with people with learning disabilities... (A1)

A particular difficulty in relation to hospital admissions appeared to be the expectation on the part of hospital staff that residential care workers would remain with, and provide care for, their tenants while they were in hospital:

...some hospitals assume because you are a care provider that you provide 24-hour care at the time when (tenants) were in hospital but (name of organisation) policy is that (you remain) until that person is booked in and settled and comfortable and then all we provide is a visiting service. So there can be frustrations from the nursing staff ... they expect people to be there for longer periods of time. (E2)

Two key barriers were noted as preventing staff from providing full-time support within acute hospital settings: difficulties with insurance cover and also the fact that while houses may be funded to provide 24-hour care; this is usually for a group of people who live together and funding levels may preclude individual 24-hour support being provided for someone in hospital. A lack of understanding of the nature of social care support can also lead to problems on discharge:

There is not an understanding of what is needed and what is in place. It is OK to say that someone has 24 hours support in their own home ... that does not mean that they can just be discharged without any amendments or changes. (A1)

Another participant (E2) commented that this lack of effective discharge planning for a tenant whose mobility had deteriorated significantly led to readmission to hospital within a very short period of time.

Participants discussed the importance of *record keeping*. Some indicated that all health-related contacts are recorded:

...all of that will be recorded and every single visit to any professional ... It is recorded on a medical contact form. Every visit to hospital, any emergency ... All of that is recorded and detailed, they are reviewed and anything actioned. There is an area on there 'To be actioned'. (A1)

Such records therefore appear to provide a means of communication between members of the staff team and aim to promote better continuity of care and support. This was noted by one participant (D3) as being important because staff teams within individual houses change over the time and knowledge of someone's medical history may otherwise be lost.

One way in which all participating organisations were seeking to improve communication with health-care staff was via the development of health passports or 'traffic light' records that would accompany tenants if they were admitted to hospital. Such records detail important aspects of the individual's care and support needs to enable health staff to provide safe, person-centred care. This is particularly important when the individual with an intellectual disability has difficulties in communicating their own needs and one participant (E2) reported that positive feedback had been received from nursing staff regarding such documentation. However, these documents were not always used by hospital staff:

I mean we sent down the admission form. The red, amber, green (traffic light system) which I said is all documented and they had lost that ... I just feel sometimes the information is going and they don't always have time to sit and look at the information that is provided for them. (E1)

Due to lost documentation, one participant (E2) reported that they had instituted a system whereby hospital staff were asked to sign to confirm that they had received it.

A few participants specifically mentioned *medication* as a key part of their role in monitoring and maintaining the health of their tenants. Particular areas of concern here seemed to be the side effects of medication, interactions between medications and medications possibly masking conditions:

The other thing is ... because they are on so much medication ... its awful hard to work out if they have any type of dementia. (C5)

The consequences of ageing

Many participants reported noting *signs of ageing* among the people they support such changes being related to cognitive decline, sensory loss, mobility problems and a general 'slowing down':

They take a lot longer to support ... They need more healthcare. They will have more visits to the hospital. (C4)

As you get older then you do get more frail and weaker. I have one service user he can fall quite a lot but it is just his age. (D2)

Generally, there seemed to be a willingness to support *ageing in place* and some spoke of 'fighting' to keep people within their own home. In some instances, this was motivated by the view that people have a right to remain within their own home (B1) but there was also recognition that it can be difficult to find appropriate alternative placements for older people with intellectual disabilities:

...they need more support ... but because of their age they cannot go into a new intellectual disability service but because of their needs they don't fit into the general population in a nursing home. (A1)

However, supporting tenants with increasing levels of frailty who require additional levels of support can have financial implications as well as impacting on both other tenants and staff. There may, therefore, come a point at which transition to another setting is necessary:

I think more or less we are able to get staff up to a level where they are able to support up to a certain level until it requires nursing care, proper nursing care. That is when it all falls apart. (C2)

As well as staffing issues the physical environment can also affect whether tenants are able to stay within their current accommodation and hence participants highlighted *the need for environmental adaptations*:

I have seen some fabulous work, where someone's needs have changed so dramatically that they need a new bathroom, walk-in shower, different height toilet, moving sink ... (B1)

Despite the challenges, some participants spoke of providing *end-of-life care* for the tenants they were supporting even when this meant they were providing what might be viewed as 'nursing' care:

The one gentleman we nursed at home and he had a hospital bed and the district nurses were giving us support with that ... The staff team did go over and above because they were nursing him. (C2)

Another participant (D2) spoke of trying to secure hospice accommodation for a tenant who had subsequently died of cancer but that the hospice would not take him as he had an intellectual disability. Others spoke of tenants dying within hospital with one commenting that her staff had secured honorary contracts to provide additional support within the hospital to ensure that the tenant had '...the best care possible' (C3).

Relationships

Relationships emerged as a key theme in relation to identifying and meeting the health needs of older people with intellectual disabilities. The first aspect, *knowing the person* with an intellectual disability, related to both the staff supporting individuals and to the healthcare professionals involved in their care. Such relationships were viewed as important in terms of recognising changes in health status and also in terms of providing a basis for effective working:

...the staff obviously know the service users and if there are any changes then they just relay them back to me. (D2)

The local surgery no problem because our home where I am has been there for 30 years, they are so well known to the clients you know. (A2)

However, within relationships with tenants, the importance of appropriate *boundaries* was also recognised with most participants referring to specific organisational policies relating to this issue. Such policies were viewed as protecting both tenants and staff.

Another important dimension to relationships that emerged from the data was the extent to which their *relationships with health professionals* impacted on the ability of residential support workers to meet the health needs of tenants. Such relationships were identified as being with staff in primary and secondary care settings as well as with professionals working in specialist intellectual disability services. Positive relationships not surprisingly had a positive effect:

I have got a good working relationship, because I think it is important anyway. We have some clients who have regular visits to the psychologists or the psychiatrists ... Even down to the secretaries of the consultants, I have got to say that I could not think what it would be like without them. (C3)

The importance of being able to contact a named person and having long-term working relationships was stressed although the potential for high levels of staff turnover to militate against this was also commented on (E3). Some participants had prior

experience of working within healthcare settings and recognised the relationships they had previously formed enabled them to get better access for their tenants:

I know if I go to certain parts of the hospital, I will get them in straight away, whereas if it was just the staff sitting there it would be no different than for everyone else. (C5)

However, relationships were not always reported as being positive. In one instance, difficulties were attributed to healthcare staff not understanding the role of residential care staff:

I actually think ... because we have not got the labels on us of nurses or health professionals that (they think) we don't really know what we are talking about ... They will take no notice of us until we get a health professional in to help us. (C1)

Such difficulties within relationships have the potential to cause delays in people with intellectual disabilities being able to access health services.

Discussion

The findings of this study confirm that residential care workers, employed within social care services, are supporting older people with quite complex age-related health problems, despite there being no requirement that they have any prior experience or training in relation to health needs. Within this context, they adopt a number of strategies that include general monitoring of tenants' health status. CIPOLD (Heslop *et al.* 2013) recognised the importance of long-term relationships with, and knowledge of, people with intellectual disabilities in responding appropriately to the health needs of this group of people and also observed that this does not always happen. Indeed, Haveman *et al.* (2011) argued that many health conditions within this group often go undetected (and therefore untreated) by carers and healthcare staff. Within this study, participants appeared to both recognise the importance of monitoring and the need for effective relationships to underpin this process. This does, however, have implications for staffing of supported living settings as it takes time to get to know what is 'normal' for individual tenants and hence to be able to recognise when health needs change: frequent changes of staffing would militate against this.

The need for regular medical review was recognised and the majority of participants viewed supporting tenants to access annual health checks as important. These checks have been viewed as a potential means of reducing avoidable deaths

(Buszewicz *et al.* 2014). Nonetheless, while positive experiences of this process were reported, the need for staff to push for such checks to take place was also evident. The importance of social care residential support staff advocating for clients within the context of healthcare has been reported elsewhere (Webber *et al.* 2010b, Heslop *et al.* 2013) and, in common with experiences in these other studies, some participants reported that their views and experience were not always respected. While it is not possible to draw definitive conclusions, there seemed to be a sense that such difficulties arose from a lack of understanding among healthcare staff regarding the role of residential support workers. This was reported as having an impact on being able to persuade health staff of the need to take action in relation to health needs, the provision of support to tenants while in hospital and safe discharge planning. This may, therefore, be an area warranting further research and also consideration within the education of healthcare professionals. Despite these difficulties, participants also provided examples of positive healthcare experiences facilitated by the development of good relationships with healthcare staff and stressed the need to invest in such relationships to achieve better outcomes for tenants. This investment is not highlighted or explored elsewhere in the literature.

Another key strategy for addressing the health needs of older tenants was reported as being good record keeping. This is important as the medical history of this group of people is largely derived from the observations of carers (World Health Organisation 2001) and deficiencies in record keeping have been noted (Jenkins 2012, Heslop *et al.* 2013). One form of record keeping that was discussed by participants was that undertaken 'in house', whereby all health-related contacts were recorded along with any action required. While this is positive (to promote continuity within and between staff teams), it was beyond the remit of this study to review any of these records, and in the absence of any health-related training and experience, the quality of such records is unclear. In addition, elsewhere in the current study, some managers raised concerns regarding the literacy and numeracy levels of support staff (Northway *et al.* 2016) which does, in turn, give rise to concerns regarding the quality of record keeping by such staff. In research undertaken in Australia, record keeping was identified as a key training need for staff supporting older people with intellectual disabilities (Wark *et al.* 2014). This may, therefore, be a further area for additional research as well as an issue that needs to be addressed within induction programmes for social care workers.

CIPOLD (Heslop *et al.* 2013) advocated the use of hospital passports to promote person-centred care for people with intellectual disabilities within acute healthcare settings although only 19% of their participants had such a document. In the context of this study, it was positive to note that the majority of services reported that they had developed such resources for tenants. However, of concern was that such documents were also reported as being lost and/or not read within healthcare settings. Similar findings are reported elsewhere (Webber *et al.* 2010b) and research as to why this should be the case seems warranted given evidence that they can enhance nursing care (Heslop *et al.* 2013) and the fact that secure storage of records is a professional requirement of nurses (Nursing and Midwifery Council, 2015). Consideration should also be given as to how awareness of the importance of such documents can be raised among healthcare staff both within their pre-qualifying education and through continuous professional development.

Despite efforts to promote and maintain the health of older tenants, some participants recounted experiences of being faced with difficult decisions as to whether they could enable tenants to remain within their homes as their health deteriorated and frailty increased. In keeping with other studies, they spoke of 'fighting' to keep people in their own homes and a sense of failure where this was not possible (Wilkinson *et al.* 2005). In this study, as in others, both the capacity of staff to meet increased needs and environmental conditions were factors that influenced decision-making (Wilkinson *et al.* 2005, Webber *et al.* 2010a, Bekkema *et al.* 2015). However, the lack of suitable alternative placements and financial implications was also reported in the current study as relevant factors. Such a situation reflects that noted by Bigby (2008), whereby a failure to co-ordinate service provision for those with intellectual disabilities and those for older people leads to people with intellectual disabilities not being supported to age in place. Given the growing numbers of older people with intellectual disabilities (Haveman *et al.* 2011) and given that they often experience complex health problems (Hermans & Evenhuis 2014), it would seem there is an urgent need for greater planning for this client group to ensure that appropriate services are available when needed: changes are needed to both policy and practice.

Limitations

It is recognised that this is a relatively small scale exploratory study involving participants from only

one area of the United Kingdom and hence it is not possible to generalise from the findings. Nonetheless some key issues have emerged that add to the growing body of international knowledge regarding the support of older people with intellectual disabilities and some areas for practice, policy and research development have been identified.

Conclusion

From this exploratory study, it is concluded that residential social care staff seek to ensure that the age-related health needs of their tenants are identified and met although challenges are also noted which give rise to the need for both practice development and further research. Two key areas are proposed namely a focus on increasing understanding among healthcare staff of the role of residential social care workers and a focus on improving health-related communication (to include both the use of hospital passports and the quality of health-related record keeping within supported living settings).

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Note

¹ Detained under the Mental Health Act 1983.

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