

Supporting persons with Down syndrome and advanced dementia

Challenges and care concerns

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Abstract

Aim: To understand staff perceptions of critical issues in caring for persons with intellectual disability (ID) and advanced dementia.

Background: There has been growing interest in addressing resource, training, and service redesign issues including an increase in collaborative practices in response to the growing incidence of dementia among persons with ID. Most recently this has included consideration of the specific issues in advanced dementia.

Method: Thirteen focus group interviews were held involving staff in six ID services and one specialist palliative care provider in Ireland. A qualitative descriptive approach was taken to analysis.

Results: Staff identified three key themes: (1) readiness to respond to end of life needs, (2) the fear of swallowing difficulties, and (3) environmental concerns and ageing in place.

Discussion: Four underlying issues that emerged in this study offer clues to solutions: (a) differences in staff preparation associated with settings, (b) lack of understanding and lack of collaboration with palliative care services, (c) uncertainties about the ability to transfer existing palliative care models to persons with ID and dementia and (d) the need to develop training on end stage dementia and related care approaches.

Keywords carer; dementia; intellectual disability; palliative care; qualitative research

Introduction

Dementia is an irreversible, progressive, organic disease that has multiple causes (Prasher, 2005). The most common type of dementia is Alzheimer's disease. The increasing survival of people with intellectual disabilities (ID) into old age also means greater numbers of individuals surviving into the age of risk where they are developing Alzheimer's dementia (AD). This is particularly true for older people with Down syndrome (DS) who are uniquely at risk of developing AD at earlier ages. Current estimates are that 15–40% of persons with DS over the age of 35 present with symptoms of dementia and that their related declines are precipitous (Prasher, 1995; Prasher et al., 1998). Onset is also earlier, mean age of dementia in persons with Down syndrome is estimated to be 51.3 years.

Coping with and addressing the needs posed by dementia are a new concern for ID services. Living to old age is a relatively new experience for persons with ID and the mandate and emphasis in ID services has been on the promotion of independence and choice; the different issues when AD is present are challenging staffing approaches and philosophies (McCallion & McCarron, 2004). Also, in Ireland and elsewhere the financing of services has been based upon assumptions of fixed needs for persons with ID. Responding to the changing needs when symptoms of dementia present, particularly in terms of new needs for 24 hour staffing, increased medical costs, and the need for capital support for environmental modifications is a new challenge that has not been planned for (Janicki et al., 2002). Nor is there one response to dementia that will meet all these new needs. This is a disease that presents in stages and each stage has its own unique challenges.

Dementia and co-morbid health conditions in persons with ID

People with DS and AD often experience an early and precipitous decline in cognitive functions and skills (Prasher et al., 1998; Visser, et al., 1997), pose behavioural and care concerns such as wandering, sleep disturbance and incontinence and may present with auditory and visual hallucinations (Cooper & Prasher, 1998; Cosgrave et al., 1999; Holland et al., 2000; Tyrrell et al., 2001). There is agreement that ageing persons with DS and dementia experience the same range of health care concerns as persons from the generic population, however frequency of these problems is often increased in persons with DS (Cosgrave et al., 2000; McCarron, 2002). It is also suggested that persons within severe and profound ID tend to have increased co-morbid conditions and require more intensive medical

and nursing care supports (O'Brien, 2001). Moss & Patel (1997) report significant differences suggesting poorer health in persons with AD compared to persons without AD. Differences were in balance, falls, gastrointestinal disorders, night-time incontinence, diarrhoea, malnutrition and musculoskeletal disorders. Other studies have also reported an association between depression and AD in persons with DS (Meins, 1995; Tyrrell et al., 2001). The combination of existing life-long disability and new compromises due to dementia will also mean that what would otherwise be considered relatively small changes in functioning in the general population become major changes for a person with ID reducing independence and increasing the impact of co-morbid conditions. As the disease progresses the impact also increases. Understanding the clinical picture at advanced dementia is imperative in order to fully understand the care implications and resources required to provide care.

Clinical picture at advanced dementia in persons with DS

Advanced dementia refers to progressive immobility, total dependence in essential activities of daily living such as bathing, washing and dressing; nutritional difficulties and severe dysphasia resulting in swallowing difficulties and propensity to aspirate; infections related to immobility and general complications of the disease. The final stages and clinical presentation of dementia in persons with DS is characterized by the following changes:

- Neuro-cognitive: Progressive worsening of memory, profound confusion and disorientation, apathy, inability to verbally communicate, weakness and fatigue, seizure activity, unresponsiveness and coma.
- Functional: Immobility and hypertonia, total assistance in all ADLs, and incontinence.
- Nutritional: Loss of appetite, difficulty in eating, swallowing difficulties and a propensity to aspirate.
- Co-morbid health conditions: Respiratory difficulties, recurrent infections, constipation, and the general complications of immobility.

(McCarron, 2002; McCarron et al., 2005a; Cosgrave et al., 2000).

Epilepsy, respiratory difficulties and other co-morbid conditions

McCarron et al. (2005a) reported epilepsy to be particularly associated with end stage dementia with 84% of the population studied having seizure activity. Such high prevalence of epilepsy demands careful and skilled assessment and 24 hour supervision as well as prompt and appropriate

response in terms of medications, oxygen, and positioning. These are not traditionally services provided in ID community settings.

Lung disease, manifested by chronic and recurrent infections, pneumonia, and dyspnoea and breathing difficulties has also been associated with persons at end-stage dementia (McCarron et al., 2005b; Prasher, 1995; Cosgrave et al., 2000). In addition, managing distressing symptoms such as pain, constipation, dyspnoea and fevers are not uncommon care requirements. Supporting persons with advanced dementia demands a high level of skills and intuitive ability. Due to difficulties in communication and an inability to self report symptoms and an atypical presentation, it has been reported that many infections are often at an advanced stage before any diagnosis is made (McCarron et al., 2005b). It is well recognized that infections such as pneumonia, urinary tract infections and septicaemia are not uncommon in late stages of dementia and are the most frequent causes of death in the terminal stages of the disease (Mitchell et al., 2004; Morrison & Siu, 2000).

Nutrition and hydration concerns

Feeding difficulties/challenges experienced as part of end-stage dementia by persons with ID mirror those described in the generic care literature in persons with AD (Biernacki & Barratt, 2001; McCarron & McCallion, 2007; Norberg et al., 1994). Lack of ability to self-feed, difficulty holding food in mouth, chewing and swallowing concerns, agitation and distress, spitting, and food inhalation/aspiration culminate in stress for the person, the family and staff (McCarron, 2002). Again, ID services are rarely well prepared for such challenges; staff carers watching someone they know and care for who is now unable to eat/drink have described feelings of guilt and remorse when faced with this concern (Service, 2002). Eating difficulties, propensity for aspiration and choking incidents present formidable clinical and care challenges. More work is needed on understanding both the advanced stages of dementia in persons with ID and on how carers may be better prepared to support quality of life in one's final days. As a first step a study of staff carers was undertaken.

Study design

A cross section of intellectual disability service providers and a specialist palliative care provider in the Republic of Ireland were involved in the study. The overall study aim was to explore the experiences of staff in intellectual disability and specialist palliative care services in supporting persons with intellectual disability and advanced dementia and to develop a training intervention to address cross training concerns (McCarron et al., 2008).

The focus in this article is to report on and discuss the findings on the challenges and care concerns identified by staff carers.

Study population

There were a total of 57 participants in the 13 focus groups. Fifty participants were drawn from six intellectual disability service providers in the Greater Dublin area of Ireland. Seven participants were drawn from one specialist palliative care service in the same catchment area.

Data analysis

Initially, analysis of the focus group data was undertaken manually, followed by the use of computer-assisted qualitative data analysis software (QAQDAS), NVivo 7 (QSR International, 2006). This combined approach was used to maximize thorough analysis. Qualitative content analysis was used as it is the choice most suitable for descriptive qualitative research and it is naturally oriented to the presentation of a summary of the informational contents of the data (Sandelowski, 2000). Codes were generated from the data and systematically applied throughout the analysis. During the course of the interviews, the interviewer incorporated constant comparative analysis which validated and confirmed the participants' descriptions and meanings against concepts which had emerged from previous interviews. Further validation involved exhaustive discussion and verification with other members of the research team.

Findings

Three themes emerged from the focus group data: (1) readiness to respond to end of life needs, (2) the fear of swallowing difficulties, (3) environmental concerns and ageing in place.

Readiness to respond to end of life needs

Staff expressed that they had limited experience of caring for the dying and supporting the person through death. Some spoke of the anxiety that this caused as almost being palpable:

... I thought my God she can't die now when I'm here because I won't know what to do . . . and even that experience alone of thinking what if she dies what will I do or if she's dying what am I going to do . . . I've no experience so what do I do? . . . (2.1.4)

Yet these were also staff that cared but who felt that they did not have the resources to provide care when dementia is at an advanced stage:

. . . my experience is that if you said to the nurse would you like us to take Mary and bring her somewhere else, you know, for the end stage they would probably say no . . . even though they are very overworked and over-stretched providing care to everybody else who doesn't have dementia on the unit . . . (7.1.1)

Many staff looked forward to a future time when such resources would be available but for now felt ill-prepared:

. . . it has a huge impact unless you have . . . staff that are actually qualified . . . em the last few days em are very intense and I don't know whether the community houses would actually be able to physically and emotionally manage with the service users that they have . . . obviously it's a huge impact on them . . . now in saying that . . . in years to come if the proper supports were put in place . . . maybe if they had a team that were mobile that you could put working within a unit that . . . the ideal thing would be if you had facilities there yes! Cause ideally it would be nice for people to die at home . . . (5.1.1)

For some, support from palliative care providers was critical particularly in the management of care issues such as pain, symptom management, nutrition and hydration:

. . . I definitely would want input . . . you know . . . while we would be able to do the basics . . . I would like a visit to see how . . . just encouragement to make sure we were doing it right and everything and . . . just to monitor it . . . (6.1.2)

Yeah, yeah, during this last stage, dealing with the family and this you know . . . that is where it comes in . . . the palliative care. (5.2.1)

Yet most felt that the good quality care they provided was not really what would be described as palliative.

. . . That's a hard one, I suppose we do a certain amount of palliative care unknowingly . . . We wouldn't maybe call it that . . . (10.1.3)

. . . So it is, I think it is in a different way but we don't call it palliative . . . (10.1.5)

. . . they are not really, maybe later on . . . once they get their diagnosis they are not, no, they are not. They are still being loved and nursed but they are not, you don't look on them as palliative care . . . if anything she has improved since she came here . . . so you know, you query, you know, so you can't just look at someone and say the death sentence . . . (3.2.2)

The fear of swallowing difficulties

Participants spoke about the 'fear' of feeding individuals with swallowing difficulties, and the anxiety it generated as evidenced in these quotes:

... we had to have the thickener as well but then what happened was she would take minor seizures as she was eating, that was scary, kind of she'd be going to eat and then she'd go into this and that really was very frightening and then she'd get a fright with whatever was there and wouldn't eat it at all, you know that kind of way ... (10.1.5)

... we continued feeding with liquidised meals and so forth and that individual got a lot of chest infections ... and you know it was difficult to feed that person ... (4.1.1)

Participants equally expressed their concerns about using PEG tubes with this population:

... well it was awful ... wasn't actually taking out the peg feed ... it was please take it out because the person was just ballooning you know ... it was as if the person was going to burst you know ... but em ... and then it was just sort of ... the time then that the person had left ... (4.1.2)

... it was absolutely horrendous eh and you have like a dietician's point of view where they want you know calories intake to be still maintained ... it's very hard to nurse someone when I know I'm doing that to them ... if I know that I can keep them re-hydrated can that not be enough at that stage when they're actively dying. (3.1.5)

Addressing end of life care needs and in particular related nutrition and hydration issues has therefore become a new, difficult and an increasingly pressing concern for family, carers and health professionals in ID services.

Environmental concerns and ageing in place

Despite the obvious burden at times, it was evident from the narratives that staff went to great lengths to keep the person in their current home. The following excerpt gives some insight into this resistance to letting go:

... if we've looked after them all those years and ... sort of grown with them like you know it's very hard when they're at the end stage of their life to ... to send them off to another unit ... and it would be our last option ... we/it would really need ... we'd have to be in a position whereby we could do no more ... you know ... (6.1.2)

Participants across all six ID sites appeared to generally support an ageing in place model but also acknowledged that this was often difficult to sustain. High levels of incontinence at advanced dementia combined with growing mobility concerns meant assistive environments were required including bathing and showering facilities, along with more adequate space to support ease of care. Staffing ratios also were reported to pose problems. Several homes had shifts where only one member of staff was available and there were also situations where awake staff were not

routinely assigned at night. Generally more than one staff member was required when someone in the home had advanced dementia and required additional support with toilet hygiene and other related personal care needs. Despite their best efforts, staff graphically described that it was often not possible to continue to give care with comfort or with safety in the person's own home as evidenced in the following quotes:

... at the very end stages where their environment absolutely you know is unsuitable for ageing because of physical restraints such as you know hoists, transfers, bathing, and all the rest it becomes completely impractical ... (7.1.2)

... there is a certain stage where you can say sorry ... there is still too much noise here, you know ... let the person stay with us as long as possible, for as long as they're comfortable. But it gets to the stage all right where you have to say no, the noise levels wouldn't be conducive to someone that was unwell, you know ... (3.2.2)

Discussion

It has previously been reported that many ID services are poorly prepared to meet and respond to the increasing care needs at end stage dementia in terms of both suitability of the environments and skill mix and knowledge base of staff (McCallion & McCarron, 2007). The responses from the staff participants here confirm these concerns.

Staff supporting persons with DS and advanced AD indicated that they are challenged in addressing the care needs of this increasingly at risk and vulnerable population. On the one hand they do wish to support ageing in place and they see good quality day-to-day care as what they do best, but did not necessarily equate this with palliative care. However, there was evidence that they would welcome assistance with symptom management, nutrition and hydration concerns and that they felt unprepared to address complex end of life care needs. Additionally, staffing, training and environmental aspects of the care setting were lacking. These challenges have been identified before (see for example, McCarron & McCallion, 2007; Tuffrey-Wijne, 1997) as have the dedication and caring of many staff carers but solutions require more than the identification and description of problems. Underlying issues of concern that emerged in this study offer clues to solutions: (a) differences in staff preparation associated with settings, (b) lack of understanding and lack of collaboration with palliative care services, (c) uncertainties about the ability to transfer existing palliative care models to persons with ID and dementia and (d) the need to develop training on end stage dementia and related care approaches.

(a) Staff and settings Living arrangements were often established and staffed to serve different purposes and populations. For example, in community settings in Ireland social care workers / care assistants deliver the majority of support and often have limited skills and education in supporting persons who are dying. Additionally nursing staff working in/or supporting these settings were often themselves educationally unprepared and they acknowledged a lack of the skills and confidence to respond to the complex needs of persons with end stage dementia.

(b) Palliative care approaches It is increasingly accepted that palliative care principles should be applied to the care of persons at end stage dementia (Abbey, 2003; Evans, 2002; Shuster, 2000; Mitchell et al., 2004; Chang et al., 2005), however despite this intent it is frequently not evident in either generic dementia let alone in persons with ID and dementia. End-of-life care models in the hospice and palliative care fields primarily address chronic illnesses such as cancers and are only recently being applied to AD (Corr et al., 2004). The Report of the National Advisory Committee on Palliative Care (NACPC, 2001) recommended the extension of specialist palliative care services to persons with progressive and advanced disease of non-cancer aetiology and the inclusion of at risk groups including persons with ID. This is not yet the case and extension of palliative care is challenging; a recent review reports lack of empirical data on the palliative care needs of this vulnerable, at risk population (Tuffrey-Wijne, 2003). While staff state they support offering death and dying care in principle, they do not feel they had the expertise in practice (Tuffrey-Wijne, 1997). The staff here had similar concerns.

(c) Transfer of palliative models It remains to be demonstrated if the knowledge gained in other fields such as cancer care will transfer easily to populations with terminal diseases such as dementia. There are also additional challenges particularly around the lack of recognition and acceptance that dementia is a terminal illness which will ultimately lead to inevitable decline and death. While not unique to the field of intellectual disability it is a particular challenge there because again services and families are more accustomed to a philosophy which has traditionally been underpinned by enhancing skills and independence versus dealing with decline and death; furthermore defining the terminal stage is often confounded in persons with ID due to level of pre-existing intellectual impairment and sometimes pre-existing high dependence.

(d) Training on end stage disease and care Staff supporting persons with DS and advanced dementia in many cases may not understand that

the person is dying and interpret decline and change as 'new symptoms' whereas palliative care principles would be better applied rather than active intervention (McCarron & McCallion, 2007). This is not unique to the field of ID and in generic care settings there is also increasing concern regarding lack of palliative care approaches at end stage dementia and often inappropriate burdensome and nonpalliative interventions are evident during the terminal and dying phase of this illness (Aminoff & Adunsky, 2006; Mitchell et al., 2004; Morrison et al., 2004). Despite the fact that is generally accepted that palliative care principles should be extended to other groups with terminal type illness, much work remains to be done from a policy, resource and educational perspective to operationalize this intent (Lloyd-Williams & Payne, 2002; Luddington et al., 2001).

Designing solutions There are training and resource challenges which must be addressed if ID services are to be readied to address advanced dementia care needs. The development of a collaborative training program between ID services and a specialist palliative care provider are one example of how to pave the way for better understanding and new approaches to care for persons with end stage and terminal dementia (McCarron et al., 2008; Fahey-McCarthy et al., 2008). Equally, while no country has achieved an optimal model of service provision, there are emerging models of good practice. New approaches in Ireland are exemplified by the strategic planning process at the Daughters of Charity Service which has supported the opening of a memory clinic, identified current persons with symptoms, estimated the potential for additional persons with dementia, examined the dementia capability of each residential unit, proposed and supported the implementation of training for all staff and informed the design of new residential units (McCarron, 2005). Elsewhere the opening of a dementia specific unit by St Michael's House has been informed by best national and international environmental and care practices in both dementia care and ID services care, and other providers are now looking at both specialized units and the redesign of existing facilities. Another important development has been the offering of a Post Graduate Diploma in Dementia and Intellectual Disabilities by the School of Nursing and Midwifery, Trinity College Dublin which is producing a core group of specialist nurses to lead change efforts. Similar efforts are occurring in other countries and offer hope for new models of services which better support people with ID and advanced dementia. Much work is still needed to ensure that emerging alternative approaches are available for all persons with ID and dementia but the prospects are now better that care services will be appropriately redesigned.

Conclusion

This paper has discussed the challenges and issues identified by staff carers associated with supporting persons with Down syndrome and advanced dementia. These difficulties include a lack of resources, training and a basic understanding of dementia in ID services, under-developed palliative care approaches for dementia and the often devastating impact of higher levels of co-morbid health conditions on the independence of the person with ID.

This paper demonstrates the need in ID services to address resource issues, develop training packages and to rethink the approaches to service delivery when dementia is present. For this to happen policy makers and health funders will also need to be encouraged to work with intellectual disability services and clinicians to develop and fund humane and appropriate services necessary to address and respond to the changing care requirements of an increasing ageing population of persons with Down syndrome and dementia. In addition, encouraging the interface between generic ageing services, intellectual disability services and specialist palliative care services will help provide seamless and cohesive care for persons living and dying with terminal and advanced dementia. The future is now; nothing would have a greater impact on the care of persons with intellectual disability and advanced dementia, than working together and instituting the knowledge we collectively have to improve quality of life and of death.

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