

*PALLIATIVE MEDICINE* editorial (accepted for publication 15/04/2016)

Developing research, policy and practice in palliative care for people with intellectual disabilities will benefit everyone

I.Tuffrey-Wijne, L.Curfs & L.Deliens

## **Developing research, policy and practice in palliative care for people with intellectual disabilities will benefit everyone**

**Irene Tuffrey-Wijne** (corresponding author)

*Associate Professor in Intellectual Disability & Palliative Care*

Faculty of Health, Social Care & Education

St. George's, University of London & Kingston University

2nd floor Grosvenor Wing, Cranmer Terrace, London SW17 0RE, UK

I.Tuffrey-Wijne@sgul.kingston.ac.uk

**Leopold Curfs**

*Director, Governor Kremers Centre*

Maastricht University Medical Centre, Netherlands

leopold.curfs@maastrichtuniversity.nl

**Luc Deliens**

*Professor of Palliative Care Research*

Director of the End-of-Life Care Research Group, VUB & Ghent University, Belgium

Luc.Deliens@vub.ac.be

People with intellectual disabilities are a sizeable minority group, making up approximately 2% of the population. They need specific attention when they reach the end of life. Whilst many of the palliative care needs of people with intellectual disabilities may be no different from those of the general population, they often present with unique issues, challenges and disadvantageous circumstances that make it more difficult to meet those needs.

It has been shown decisively that people with intellectual disabilities have poorer health outcomes than the general population for reasons unrelated to the causes of their cognitive impairment, but rather, due to failings within healthcare systems. This is compounded by persistent negative attitudes and assumptions about quality of life of people with life-long cognitive impairments.<sup>1,2</sup> These failings are not limited to acute hospital services or social care settings. In 2013, the Confidential Inquiry into Premature Deaths of People with Intellectual Disabilities (CIPOLD), which investigated the deaths of 247 people with intellectual disabilities, reported that

“people with [intellectual] disabilities were less likely than the comparator group of people without [intellectual] disabilities to have access to specialist palliative care services and received less opioid analgesia in their final illness. Their deaths were sometimes described as not being planned for, uncoordinated and poorly managed.”<sup>3</sup> (p.119)

The specific challenges for palliative care services have been well described<sup>4,5</sup>. They include lack of knowledge and experience among palliative care staff in caring for people with intellectual disabilities; problems with symptom recognition and management; severe

communication challenges; patients' difficulties in understanding complex concepts including death and dying; multiple co-morbidities; and complex social situations.

In 2015, the European Association of Palliative Care published a White Paper titled *Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe*, which was produced with the involvement of 92 experts from 15 European countries<sup>6</sup>. Its recommendations include that (a) palliative care services should actively reach out to find the population of people with intellectual disabilities within their catchment areas; (b) there should be on-going exchange of experiences, expertise and best practice on local, national and international levels; and (c) there is a need for further research, as empirical evidence in this field is limited.

Service providers, policy makers and funders may well ask whether it is worthwhile spending time and resources on research, training and preparation for supporting patients with intellectual disabilities, as they may see very few such patients within their service. However, the importance of focusing on practice, policy and research in relation to people with intellectual disabilities goes beyond the obvious need to ensure that vulnerable people are provided with the high-quality care everyone deserves at the end of life. The skills needed in order to care for this group of patients are eminently transferrable. Looking carefully at the difficulties they face can teach us much about the need for improving services, which will benefit all patients.

With regards to policy and practice, addressing the challenges faced by people with intellectual disabilities at the end of life requires a sustained focus. Care providers, including palliative care staff, will need help and support in meeting needs that are likely to be unfamiliar. Collaboration with other services, including cross-professional training (for example, between palliative care experts and intellectual disability experts), is particularly important. There are now many examples of such collaborations (with other services and with family carers) leading to excellent practice that is strongly person-centred (see [www.pcpld.org](http://www.pcpld.org)).

On an organisational management level, services must be prepared to care for people with intellectual disabilities by making 'reasonable adjustments' to their usual service delivery. This may include, for example, the provision of easy-read information, extended appointment times, facilities to have a carer to stay, structures to involve carers in planning and delivery of care as a matter of course, and staff training in mental capacity laws or assessment of symptoms in non-verbal patients. However, the needs of people with intellectual disabilities are highly variable and could be rather unexpected, so listening to carers is essential. Organisations that can adapt and adjust their services for individuals with

intellectual disabilities are likely to have the flexibility to meet the widely variable needs of most patients.

On a policy level, the creation of specific care pathways for people with intellectual disabilities should trigger early referrals. Timely access to palliative care expertise is best ensured if there are easy lines of communication between palliative care services and social care services that provide support for people with intellectual disabilities in their homes (whether it is in residential care settings or in supporting people who live with their families). For any person with an intellectual disability, the diagnosis of a long-term or terminal condition should trigger proactive care planning, including plans for end-of-life care.

With regards to research, those of us who have focused on the palliative care needs of people with intellectual disabilities have learnt much during the past few decades. For example, research into effective ways to communicate about life-changing and life-limiting illness with people who have intellectual disabilities, including those with the most profound cognitive impairments, has led to the development of a new holistic model for breaking bad news that takes account of the person's background, personality, cognition, social circumstances and available support<sup>7</sup>. Such a communication model may well be worth testing in other patient groups.

Providing person-centred care incorporates involving patients in decision-making. The processes for shared decision-making with people who have cognitive impairments are not always understood by healthcare staff. We have found that people with intellectual disabilities are often left out of decision-making when they should have been involved, perhaps due to erroneous assumptions about their mental capacity or a lack of knowledge about how to involve people with cognitive and communication impairments in a meaningful way<sup>8</sup>. It is not difficult to see that staff who can involve people with intellectual disabilities in decision-making can do the same for all their patients, regardless of their vulnerabilities. Developing and sharing expertise in this area will therefore be of benefit for all.

Advance Care Planning (ACP) for people with intellectual disabilities is another area where the benefits are likely to go beyond this one group of patients. Physicians and other healthcare professionals find it difficult to initiate ACP processes with their patients and families<sup>9</sup> and may well be inspired by the development of the simple models, processes and documentation that people with intellectual disabilities require. There have been a number of initiatives in the Netherlands and the UK aimed at making ACP accessible to people with intellectual disabilities, but rigorous testing and evaluation has been lacking so far.

Researchers in the field of intellectual disabilities hold valuable expertise around inclusion. Undertaking participatory research with people with intellectual disabilities has led to the discovery of ways to adapt the standard research processes, so that they are accessible to people who are usually excluded from research<sup>10</sup>. One such example is the study by Bekkema and colleagues, who used creative ways to investigate the views of people with intellectual disabilities around care relationships at the end of life<sup>11</sup>. Such studies could inspire researchers working to improve palliative care for other vulnerable patient groups, such as those with dementia or mental health problems.

A recent document has proposed research priorities for palliative care<sup>12</sup>. These include: establishing approaches for listening to and incorporating patient views; finding the best ways to provide information and training for families, carers and staff; ensuring continuity of care; finding the best ways to provide care at home; and finding ways to assess and treat pain and other symptoms. We suggest that each of these questions could benefit from a research focus on people with intellectual disabilities. They are the patients whose communication may be the most incomprehensible, who may be the most terrified of unfamiliar situations, whose symptoms may be masked by unconventional behaviours and co-morbidities, and who have a wide and eclectic range of family, friends and support staff in their social network, making care delivery particularly complex. It is worth developing and testing service delivery improvements for groups of patients with low levels of cognition and high levels of additional challenges, in the same way as it is worth testing and validating questionnaires through groups of respondents with the lowest level of schooling or literacy.

There is growing attention for people with intellectual disabilities within the palliative care literature, including a recent paper on specific research priorities<sup>13</sup>. We believe that 'getting it right' for people with intellectual disabilities who are dying could be a benchmark for the quality of palliative care services generally. Conducting research, developing policies and improving practice in this area is not a marginal activity, but presents golden opportunities for achieving all-round excellence.

## References

1. Mencap. *Death by indifference*. London: Mencap; 2007.
2. Mencap. *Death by indifference : 74 deaths and counting*. London: Mencap; 2012.
3. Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Bristol: Norah Fry Centre; 2013.

4. Tuffrey-Wijne I, Hogg J, Curfs L. End-of-life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness: a review of the literature and available resources. *J Appl Res Intellect Disabil*. 2007;20(4):331–344.
5. Read S. Palliative care for people with intellectual disabilities: Pitfalls and potential. *Palliat Med*. 2013;27(1):3–4.
6. Tuffrey-Wijne I, McLaughlin D. *Consensus norms for palliative care of people with intellectual disabilities in Europe: EAPC White Paper*. London/Milan: European Association for Palliative Care (EAPC); 2015.
7. Tuffrey-Wijne I. A new model for breaking bad news to people with intellectual disabilities. *Palliat Med*. 2012;27(1):5–12.
8. Wagemans A, van Schrojenstein Lantman-de-Valk H, Proot I, Metsemakers J, Tuffrey-Wijne I, Curfs L. The factors affecting end-of-life decision making by physicians of patients with intellectual disabilities in the Netherlands: a qualitative study. *J Intellect Disabil Res*. 2013;57(4):380–389.
9. De Vleminck A, Pardon K, Beernaert K, et al. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences. *PLoS One*. 2014;9(1):e84905.
10. Butler G, Cresswell A, Giatras N, Tuffrey-Wijne I. Doing It Together (DM Special Issue). *Br J Learn Disabil*. 2012;40(2):134–142.
11. Nienke Bekkema, Anke JE de Veer, Cees MPM Hertogh and Anneke L Francke. Perspectives of people with mild intellectual disabilities on care relationships at the end of life: A group interview study. *Palliat Med* 2016, July: pp ?? DOI: 10.1177/0269216316640421
12. PeolcPLP. *Palliative and end of life care Priority Setting Partnership (PeolcPSP)*. London: James Lind Alliance; 2015.
13. Tuffrey-Wijne I, Wicki M, Heslop P, McCarron M, Todd S, Oliver D, De Veer A, Ahlström G, Schäper S, Hynes G, O'Farrell J, Adler J, Riese F, Curfs L. Developing research priorities for palliative care of people with intellectual disabilities in Europe: a consultation process using nominal group technique. *BMC Palliat Care*. 2016;15(36).