

## Title page

**Title:** The human rights of older people with mental health conditions and psychosocial disability to a good death and dying well

### **Authors names, highest degrees and affiliations:**

**Carmelle Peisah MBBS (Hons) MD, FRANZCP**

School of Psychiatry, Faculty Medicine & Ageing Futures Institute, University of New South Wales;  
Capacity Australia, Sydney, Australia

**Elizabeth L Sampson MBChB MD,**

Marie Curie Palliative Care Research Unit, Division of Psychiatry, University College London

**Kiran Rabheru MD, CCFP, FRCP**

University of Ottawa, Ontario, Canada

**Anne Wand, MBBS, PHD, FRANZCP**

Specialty of Psychiatry, Faculty Medicine and Health, University of Sydney; Discipline of  
Psychiatry, Faculty of Medicine, University of New South Wales, Australia

**Maria Lapid MD**

Mayo Clinic Department of Psychiatry and Psychology

**1) What is the primary question addressed by this study?**— We explore why older people with mental health conditions and psychosocial disabilities are vulnerable to human rights violations at the end of life and examine existing and potential solutions.

**2) What is the main finding of this study?**— Key to best practise end of life care are the actualisation of human rights to dignity, autonomy, self-determination and respect for will and preferences, equitable access to quality health care that is needs-based, and respect for family and relationships. Older people with dementia, those with serious mental illness, and those with intellectual disability are variably afforded these rights at the end of life.

**3) What is the meaning of the finding?**— An integrated care model that encompasses physical and mental health, palliative care, social and spiritual support must be on offer, while recognizing that good dying is needs-based and self-determined.

### **Abstract**

The human right to a good death and dying well is as important as the right to life. At stake at the end of life are human rights to dignity, autonomy, self-determination and respect for will and preferences, equitable access to quality health care that is needs-based, and respect for family and relationships. Older people with dementia, those with serious mental illness, and those with intellectual disability are vulnerable to “bad deaths” due to violations of these rights. In this paper we explore why this is so and examine existing and potential solutions. A human rights-approach to end-of-life care and policy for older persons with mental health conditions and psychosocial

disability is one that is needs-based, encompassing physical and mental health, palliative care, social and spiritual support services provided in the context of inclusive living. Most importantly, end of life care must be self-determined, and not “one size fits all.” An important remedy to existing violations is to strengthen human rights frameworks to cater specifically to older persons’ needs with a UN convention on the rights of older persons. Finally, as health professionals we have important contributions to make at the coalface by accepting our responsibilities in the area of death and dying. With the concept of the palliative psychiatrist gaining traction and recognition that death is our business, we add that human rights is also our business.

### **1. Request for Article Summary**

We explore why older people with mental health conditions are vulnerable to human rights violations at the end of life. An integrated care model that encompasses physical and mental health, palliative care, social and spiritual support must be on offer, while recognizing that good dying is needs-based and self-determined. Health professionals can make important contributions at the clinical coalface by accepting our responsibilities in this area. Death is our business; human rights are our business.

### **2. Twitter Handle**

@CapacityAus

### **3. 200-character Summary Tweet**

Good dying is needs-based & self-determined. Health professionals can make important contributions at the clinical coalface by accepting that death is our business and human rights are our business.

### **Manuscript**

The human right to a good death and dying well is as important as the right to life. However, what constitutes a “good death” remains elusive, varies from individual to individual, depending on whose perspective it is viewed from, the person, the family or the health professional.<sup>1-3</sup> In 1997 the Institute of Medicine (now National Academy of Medicine) defined a "decent or good death" as one “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards;" and a "bad death" as characterized by “needless suffering, disregard for patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended.”<sup>4</sup>

The divergent perspectives on these concepts mandates a person-centred, self-determined approach <sup>5</sup> at the core of human rights to autonomy, self-determination and respect for will and preferences. However, equally important at end of life are human rights to dignity, equitable access to highest attainable standards of health (including respecting needs arising on account of disability) and respect for family and relationships.<sup>6-8</sup> As articulated in the Convention on Rights of Persons with Disabilities (CRPD),<sup>9</sup> actualisation of these rights and the enjoyment of a positive death are equally owed to persons with disability, including older people with mental health conditions and those living in care settings, who are especially vulnerable to human rights violations. In this paper, we outline why this is so and explore potential for enjoyment of human rights to positive dying for older people with mental health conditions and psychosocial disabilities. We conclude with recommendations to drive future care and policy in this area.

Why are older people with mental health disorders vulnerable to experiencing bad deaths? Although just as with good deaths, a bad death for one person is not a bad death for another,<sup>5</sup> usually bad deaths are those that come as a surprise due to lack of communication with health practitioners and lack of advance care planning (ACP), and are associated with unrelieved symptoms and suffering, and unmet needs.<sup>10-12</sup> With regards to surprises, there has been a concerted effort to get conversations started regarding end of life for people with dementia for over 20 years. For example, The Gold Standard Framework (GSF), developed the Surprise Question (Would you be surprised if this patient were to die in the next 12 months?) to facilitate discussions between health professionals and persons with dementia and their carers to assess needs, symptoms and preferences to plan care.<sup>13</sup>

A range of initiatives encouraging ACP in care settings including early timely discussions, upskilling of staff and family conferencing have flourished, giving voice to people with dementia at the end of life and challenging paternalistic assumptions that they lack capacity to do so.<sup>10, 14-18</sup> Aligned with Article 12 of the CRPD, those with impaired capacity have been afforded supported decision making.<sup>19-21</sup> Further hope is inspired by initiatives to increase access to and optimise palliative care in long-term care<sup>12, 22-25</sup> and to address suffering and symptom relief, including management of delirium and pain in both care and acute hospital settings.<sup>26-30</sup>

Providing quality death and dying for older persons with mental illness is another matter. If we consider that persons with dementia, particularly those in care settings, are at risk of suboptimal end-of-life care,<sup>31-32</sup> efforts for those with severe and chronic mental illness are almost non-

existent.<sup>33</sup> Despite poorer physical health and increased and premature mortality rates compared to the general population,<sup>34-35</sup> people with severe or chronic mental illness have less access to palliative care and mental health services, and parlous rates of ACP.<sup>36-37</sup> These are clear violations of human rights to dignity (Articles 1 and 3, CRPD) autonomy (Article 12) and equitable access to health (Article 25).

Acknowledging rights to autonomy, self-determination and respect for will and preferences, people with severe and chronic mental illness have been “utterly neglected” in efforts to promote ACP<sup>38</sup> and their needs and desires with regards to end of life care ignored.<sup>39</sup> This is often compounded by lack of understanding amongst physicians about capacity and human rights, including the common law presumption of capacity for all adults regardless of disability, and the assessment of capacity for end of life decision making.<sup>40</sup> Yet people with severe mental illness can give voice to end of life preferences<sup>41</sup> and are equally owed rights to self-determination.<sup>42</sup>

Systemic barriers to the enjoyment of human rights fuelled by discrimination based on ageism and “mentalism”<sup>7</sup> exist across health and mandate systemic solutions. Such solutions include public mental health initiatives such as the “*Do It Your Way*” project, which integrates service delivery components such as stakeholder coalition, research, education, training and outreach for providers and patients to improve access to advance care planning and end-of-life care for persons with serious mental illness.<sup>43</sup> Sometimes positive discrimination associated with frailty, often comorbid with serious mental illness,<sup>44</sup> can serve human rights. Frailty agenda in care services can serve as useful levers to ensure equitable access to both quality care and advance planning. For example, in the United Kingdom, frailty pathways, particularly those underpinned by the Comprehensive Geriatric Assessment (CGA)<sup>45</sup> often include ACP and recognition that someone may be reaching end of life.

These complexities are echoed for older people with intellectual disability (ID) living in community care, often exposed to death and dying yet rarely given opportunity to express end of life will and preferences.<sup>46-47</sup> Assumption of lack of capacity by clinicians<sup>48</sup> based on often partial understanding about the end of life amongst older people with ID<sup>49</sup> compounded by communication difficulties,<sup>50</sup> mean that they are often totally excluded from end of life decision-making.<sup>51</sup> However, burgeoning research supports a more nuanced, supported approach to end of life care and decision-making for people with ID. For example, in care settings, understanding client responses to the death of other clients, which often fuel anticipatory grief reactions regarding their own death, provide

opportunities to talk about death and dying.<sup>49, 52</sup> Weise et al<sup>49</sup> identified opportunities to engage in such discussions including 'when family die', 'incidental opportunities', 'when clients live with someone who is dying' and 'when a client is dying'. These are all opportunities for supported decision making. Death with dignity and autonomy in a place of one's choice is equally owed to people with ID.<sup>52</sup>

## Conclusions

It goes without saying that bad deaths are bad for the dying person, but equally, bad deaths are bad for the mental health of families,<sup>53</sup> and for the moral distress of staff.<sup>54</sup> The experience of death and dying for many older people with mental health conditions has constituted elder abuse by neglect, and violated rights to be protected against abuse or torture and cruel, degrading treatment (Articles 15 and 16 CRPD). Medical assistance in dying (also referred to as Voluntary Assisted Dying, VAD) is not the solution. VAD should not be used as a substitute for humane end of life care, nor should it be a means for relieving family burden.<sup>55</sup> These violations have been worsened by the "tsunami of suffering" associated with the COVID pandemic, where quality dying has gone by the wayside.<sup>56</sup> Access to palliative care has been curtailed by demands on health systems, support from loved ones restricted, and nuanced advance care planning abandoned in favour of hasty and pragmatic "signing people up" with not for resuscitation orders to assist with triaging.<sup>6</sup>

However, many of the initiatives we have described above suggest hope. None of these challenges to quality dying are insurmountable. We offer the following human rights-based recommendations to guide care and policy for older persons with mental health conditions and psychosocial disability approaching the end of life:

1. An integrated care model that encompasses physical and mental health, palliative care, social and spiritual support must be on offer, while recognizing that good dying is needs-based and self-determined i.e. based on what the person needs and wants at the end-of-life;<sup>57</sup>
2. The model of care must be provided in a context of inclusive living options and a hierarchy of self-determined care environments, not "one-size fits all";<sup>58</sup>
3. Health care systems must expand their focus of attention from current acute medical and surgical based models for older persons requiring end of life care to holistic chronic care models that optimize quality of life;
4. VAD is a complex and deeply personal issue. Governments must be committed to ensuring that laws governing VAD meet evolving needs, autonomy and freedom of choice, and right to

safeguarding of those who are vulnerable. It is equally incumbent upon clinicians involved in capacity assessment for VAD to be mindful of these human rights obligations;<sup>59</sup>

5. Develop and implement human rights-based policies and programs in the community and in health care to combat ageism and mentalism. Strengthen human rights frameworks to cater specifically to older persons' needs by supporting a UN convention on the rights of older persons.<sup>7</sup>

Our best contributions as health professionals can be made at the coalface by accepting our responsibilities in the area of death and dying. The concept of the "palliative psychiatrist" (i.e. with palliative care skills) is receiving traction<sup>60-61</sup> as we increasingly recognise that death is our business.<sup>62</sup> We would add that human rights is our business.<sup>7</sup>

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