

*Special Article*

## Ethical Challenges and Solutions Regarding Delirium Studies in Palliative Care

Lisa Sweet, PhD, CPsych, Dimitrios Adamis, MSc, GradStat, MD,  
 David Meagher, MD, PhD, MRCPsych, MSc, MHSc, Daniel Davis, MB, ChB, MRCP,  
 David Currow, BMed, MPH, FRACP,  
 Shirley H. Bush, MBBS, DRCOG, DCH, MRCP, Dip Pall Med, FACHPM,  
 Christopher Barnes, MD, CCFP, Michael Hartwick, MD, FRCPC,  
 Meera Agar, FRACP, FACHPM, MPallCare,  
 Jessica Simon, MB ChB, MRCP(UK), FRCPC, William Breitbart, MD, FAPA, FAPM,  
 Neil MacDonald, CM, MD, FRCP(C), FRCP(Edin), and  
 Peter G. Lawlor, MB, FRCPI, CCFP, MMedSc

*Division of Palliative Care (L.S., S.H.B., C.B., M.H., P.G.L.); and Division of Critical Care (M.H.), Department of Medicine; Department of Epidemiology and Community Medicine (P.G.L.), University of Ottawa; Bruyère Research Institute (L.S., S.H.B., P.G.L.); and Palliative Care Unit (S.H.B., C.B.), Bruyère Continuing Care, Ottawa, Ontario, Canada; Research and Academic Institute of Athens (D.A.), Athens, Greece; Cognitive Impairment Research Group (D.M.), Department of Psychiatry, Graduate Entry Medical School, University of Limerick, Limerick, Ireland; Department of Public Health and Primary Care (D.D.), University of Cambridge, Cambridge, United Kingdom; Discipline of Palliative and Supportive Services (D.C., M.A.); and Flinders Centre for Clinical Change (D.C.), Flinders University, Bedford Park, South Australia, Australia; Critical Care Response Team (M.H.), The Ottawa Hospital, Ottawa, Ontario, Canada; Department of Palliative Care, Braeside Hospital, HammondCare (M.A.); and South West Sydney Clinical School (M.A.), University of New South Wales, Sydney, New South Wales, Australia; Division of Palliative Medicine, Department of Oncology and Department of Internal Medicine (J.S.), University of Calgary, Calgary, Alberta, Canada; Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center (W.B.); and Department of Psychiatry, Weill Medical College of Cornell University (W.B.), New York, New York, USA; Department of Oncology (N.M.), McGill University, Montreal, Quebec, Canada; and Ottawa Hospital Research Institute (P.G.L.), Ottawa, Ontario, Canada*

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### Abstract

**Context.** Delirium occurs commonly in settings of palliative care (PC), in which patient vulnerability in the unique context of end-of-life care and delirium-associated impairment of decision-making capacity may together present many ethical challenges.

**Objectives.** Based on deliberations at the Studies to Understand Delirium in Palliative Care Settings (SUNDIPS) meeting and an associated literature review, this article discusses ethical issues central to the conduct of research on delirious PC patients.

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*Address correspondence to:* Dimitrios Adamis, MSc, GradStat, MD, Research and Academic Institute of Athens, 27 Themistokleous Street and Akadimias,

Athens 106 77, Greece. E-mail: [dimaadamis@yahoo.com](mailto:dimaadamis@yahoo.com)

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**Methods.** Together with an analysis of the ethical deliberations at the SUNDIPS meeting, we conducted a narrative literature review by key words searching of relevant databases and a subsequent hand search of initially identified articles. We also reviewed statements of relevance to delirium research in major national and international ethics guidelines.

**Results.** Key issues identified include the inclusion of PC patients in delirium research, capacity determination, and the mandate to respect patient autonomy and ensure maintenance of patient dignity. Proposed solutions include designing informed consent statements that are clear, concise, and free of complex phraseology; use of concise, yet accurate, capacity assessment instruments with a minimally burdensome schedule; and use of PC friendly consent models, such as facilitated, deferred, experienced, advance, and proxy models.

**Conclusion.** Delirium research in PC patients must meet the common standards for such research in any setting. Certain features unique to PC establish a need for extra diligence in meeting these standards and the employment of assessments, consent procedures, and patient-family interactions that are clearly grounded on the tenets of PC. *J Pain Symptom Manage* 2013;■:■-■. © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

### **Key Words**

*Ethics, palliative care, delirium, research*

## **Introduction**

Delirium is a complex neuropsychiatric disorder characterized by acute or subacute changes to mental status with impaired consciousness, attention, and cognition.<sup>1</sup> It is particularly common in palliative care (PC) settings, with prevalence estimates ranging from 13% to 42% at admission and 58% to 88% in the weeks or hours preceding death.<sup>2,3</sup> Depending on etiologic factors, delirium episodes may be reversible in 30%–50% of individuals.<sup>4,5</sup> Although delirium is a major determinant of clinical outcomes and health care costs,<sup>6,7</sup> it is often clinically under-recognized<sup>8–11</sup> and relatively under-researched, even in the PC setting. The reasons for this are complex and involve particular ethical, clinical, and methodological challenges.<sup>12–16</sup>

The aim of PC is to relieve suffering and improve the quality of life of dying patients and their relatives.<sup>17</sup> However, this cannot be achieved without solid research to support evidence-based care. There are differing views and opinions as to whether patients who are near the end of life should be involved in research studies. Some authors suggest that research in PC should be carried out and encouraged like that in other branches of medicine,<sup>12,18,19</sup> whereas others advocate that

such patients never be asked to participate in research studies.<sup>20</sup> More moderate positions have proposed the need for restrictive guidelines, careful scrutiny, and oversight.<sup>21</sup>

As summarized by Duke and Bennett,<sup>14</sup> debates on the ethics of research in PC patients have centered on several key issues including the vulnerability of this patient population and their right to partake in research, as well as their capacity to consent to research. The study of delirium, a disorder that by its very nature has the potential to threaten the patient's decision-making capacity thereby amplifying the degree of vulnerability, is further beset with unique ethical challenges when proposed in a PC setting.

In this article, we review and discuss some of these challenges in terms of the ethical principles at the heart of deciding whether such individuals should be included in research and practical matters such as consent and capacity that arise when conducting research with individuals experiencing delirium in the PC context. Some solutions regarding the matter of consent also are proposed. Finally, we briefly address the relevant cultural and international dimensions of this subject.

Our review was informed by both a literature search and a multidisciplinary input from

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