



## Letter to the Editor: Sleep Disturbances in People with Advanced Cancer and Their Informal Caregivers: A Digital Health Exploration

Thilo Schuler, MD, MHI<sup>1,2</sup> David Currow, BMed, MPH, PhD, FRACP,<sup>3</sup>  
Katherine Clark, MBBS, MMed, PhD, FRACP, FACHPM,<sup>4,5</sup>  
and Michael Back, MBBS, MBA, PhD, FRANZCR<sup>1,5</sup>

### Dear Editor:

The recent large-scale study by Currow et al. in Australian palliative care recipients described a high prevalence of sleep-related distress and its strong association with physical symptoms.<sup>1</sup> This important study confirms and strengthens findings in smaller studies, concluding that sleep needs increased attention by clinicians and researchers to better understand and address this problem.

We are currently in the analysis phase of a pilot study to investigate the feasibility of digital health-enabled approaches in routine care. Utilizing an emerging method known as *ecological momentary assessment* we provided consumer-grade wearable “fitness” sensors to recipients of palliative care services and their informal caregivers to explore sleep, physical activity, and distress patterns.<sup>2</sup> This letter shares early data that are both congruent with and expand on the findings of highly prevalent sleep-related distress in palliative care.<sup>1</sup>

We hypothesized that emerging digital health approaches, including wearables and *ecological momentary assessments*, may provide tools for better understanding and treating sleep-related distress in people with advanced cancer and their caregivers. This study included the following:

1. Posing small surveys “in-the-moment” including when a potential noteworthy event has just happened will overcome the issue of recall bias and may reveal contextual factors that otherwise may have not been mentioned.
2. Including the caregiver as a formal research subject allows the dyadic inter-relationships affecting sleep, as well as other symptoms causing distress for the care recipient and the caregiver, to be uncovered.

3. Digital health methods provide additional opportunities for patient management such as passive monitoring for “yellow flags” using digital biomarker profiles (e.g., persistent change in sleep parameters) combined with risk-adapted patient support mechanisms when those yellow flags appear (e.g., just-in-time provision of helpful online resources for improving sleep or a phone call by a member of the clinical team).

Fifteen dyads were recruited from recipients of community palliative care and their primary informal caregiver ( $n = 30$ ). For five weeks both dyad members wore a consumer-grade wearable sensor linked to their smart phone. For the pilot’s ecological momentary assessment component participants were prompted every morning to complete a two-question survey about the preceding night on their phone. When the sensor breached an individualized “stress” level during daytime hours another two-question survey was triggered.

The mostly female (80%) palliative care recipients had advanced cancer from 10 different primary sites. Their median age was 59 years with an Australian-modified Karnofsky Performance Status of 60 to 80.<sup>3</sup> Caregivers had the same median age and all but three were spousal partners.

Analysis of the granular longitudinal dataset so far has revealed, consistent with Currow et al., that in 11% (30/261) of the daily survey responses the person with advanced cancer reported “quite a bit” or “very much” sleep disturbance with the majority providing physical symptoms as the key reason. The corresponding rate for the caregivers was similar at 12% (21/179). However, mental reasons such as worrying predominated in this group (see Fig. 1).

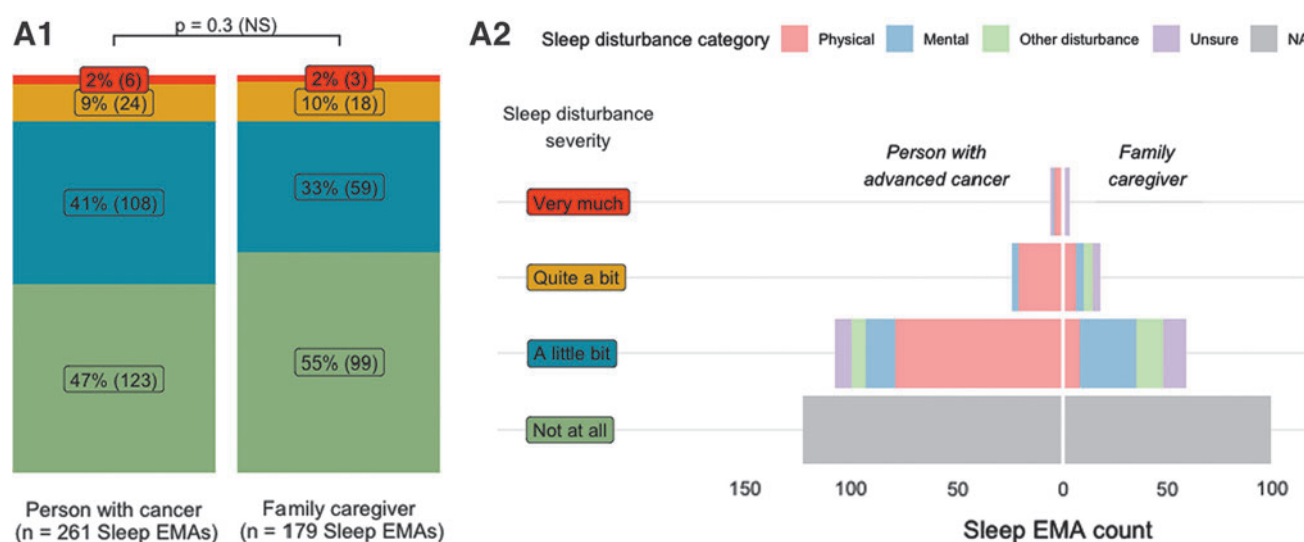
<sup>1</sup>Department of Radiation Oncology, Northern Sydney Cancer Centre, Royal North Shore Hospital, Sydney, New South Wales, Australia.

<sup>2</sup>Australian Institute of Health Innovation, Macquarie University, Sydney, New South Wales, Australia.

<sup>3</sup>Faculty of Science, Medicine, and Health, University of Wollongong, Wollongong, New South Wales, Australia.

<sup>4</sup>NSLHD Supportive and Palliative Care Network, Northern Sydney Cancer Centre, Royal North Shore Hospital, Sydney, New South Wales, Australia.

<sup>5</sup>Sydney Medical School, University of Sydney, Sydney, New South Wales, Australia.



**FIG. 1.** Responses to daily sleep survey from palliative care recipients and their caregivers: severity of sleep disturbance (A1) and reasons by severity level (A2). EMA, ecological momentary assessment.

We are in the process of further analyzing the collected dataset, with a focus on feasibility of routine care translation.

## References

- Currow DC, Davis W, Connolly A, et al.: Sleeping-related distress in a palliative care population: A national, prospective, consecutive cohort. *Palliat Med* 2021;35:1663–1670.
- Thong MSY, Chan RJ, van den Hurk C, et al.; MASCC EMA Working Group: Going beyond (electronic) patient-reported outcomes: Harnessing the benefits of smart technology and ecological momentary assessment in cancer survivorship research. *Support Care Cancer* 2021;29:7–10.
- Abernethy AP, Shelby-James T, Fazekas BS, et al.: The Australia-modified Karnofsky Performance Status (AKPS)

scale: A revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliat Care* 2005;4:7.

Address correspondence to:  
 Thilo Schuler, MD, MHIInf  
 Department of Radiation Oncology  
 Northern Sydney Cancer Centre  
 Royal North Shore Hospital  
 Reserve Road  
 Sydney  
 New South Wales 2065  
 Australia

E-mail: thilo.schuler@health.nsw.gov.au