

Maintaining Patient's Sense of Control and Autonomy at the End of Life: The Crux for a Better Ending

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Most end-of-life patients inevitably rely on the physical care from their caregivers due to the decline of their functional ability. While caregivers strive to provide the best care they can in order to maintain the comfort and quality of life of the patients, the patients themselves may feel worried that they are a burden to others, which in turn undermines their psychological wellbeing and personal value. One of the strategies to help preserve a patient's sense of self worthiness is to enhance the sense of control and autonomy in patients, so that patients can receive care consistent with their wish, choose their way of living, and live the end stage of their life to the fullest.

Autonomy and sense of control are considered by patients as one of the core factors contributing to the dignity in the end of life as well as a 'good death' according to several studies conducted on terminally-ill patients^{1 2 3}. These studies, which were conducted in either Western or Chinese culture, implied that patients' sense of personal control may be universally important, with dignity being equally important. To enhance patient's sense of personal control, caregivers should respect patient's choices and encourage patients to take part in the planning of their care and self-management, in every way a caregiver can. Particularly, to bolster personal control, caregivers should help patients to (1) feel secure through the provision of essential assistance to help them do things they cannot do, (2) be informed about their illness and options, and (3) be valued as an independent individual as much as possible⁴.

The story of Jeff T. Payne⁵ may give us a glimpse of how autonomy and sense of control can possibly enhance the quality of life of a patient with life-threatening illness. Payne is a patient

¹ Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine* 2002;54(3):433-43.

² Ho, A.H.Y., Luk, J.K.H., Chan, F.H.W., Ng, W.C., Kowk, C.K.K., Yuen, J.H.L., Tam, M.Y.J., Kan, W.S., & Chan, C.L.W. (2015). Dignified palliative care in long-term care settings: an interpretive-systemic framework for end-of-life integrated care pathway (EoL-ICP) in Hong Kong. *American Journal of Hospice and Palliative Medicine*, DOI: 10.1177/1049909114565789.

³ Mak, M. H. J. (2002). Accepting the timing of one's death: An experience of Chinese hospice patients. *OMEGA*, Vol. 45 (3), 245-260.

⁴ Lauck, S. (2009). Patients felt greater personal control and emotional comfort in hospital when they felt secure, informed, and valued. *Evidence Based Nursing*, Vol. 12 (1): 29. doi: 10.1136/ebn.12.1.29.

⁵ Exchange: Meds, treatments, help man delay 'death sentence' (2016). Retrieved from Stamford advocate: <http://www.stamfordadvocate.com/news/article/EXCHANGE-Meds-treatments-help-man-delay-death-6835904.php#photo-9415352>

who was diagnosed with congestive heart failure 15 years ago, a condition of the heart failing to pump enough blood to meet the body's needs. Congestive heart failure is a chronic, progressive and life-threatening disease without a complete cure. When Payne first learned about the bad news, he became depressed and thought of it as a death sentence. Like many other patients with heart failure, Payne suffered from the condition of heart irregularity which scared him and resulted in frequent emergency room visits in the first couple of years. Payne also knows that his condition is worsening and that his heart will stop beating anytime. "If your heart stops, you're dead and that's happened to me twice." said Payne.

However, Payne, now being 65, gradually learned to live with the disease. He achieved this not in one day but he learned about his disease and treatment options, and he was eager to learn about different strategies to manage his symptoms. He also made informed decisions to receive medical treatments which were consistent to his wish.

Payne chose to live an active life which he wanted and he outlived his life expectancy. He is allowed to do what he is able to and what he likes to do. He takes care of the house when his wife is at work and he enjoys leisure and social life such as gardening, playing saxophone, and maintaining regular exercises. The process is not without ups and downs as there are always uncertainties. Nevertheless, Payne chose not to worry about the prognosis, but to accept that he may feel unwell sometimes, and live each day as if it is his last day. "I learned what my body is doing and learned to accept it. I needed to live my life." said Payne.

Even in the end stage of life, life itself should not be forgotten and be over-shadowed by the disease. Payne's story shows us how patient's personal control and autonomy can be safeguarded by a care which helps the patient feel secure, informed, and valued, and this further empower patients to maintain an active life till the very last moment of life.