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An Unspoken need

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An Unspoken Need (Editorial)

Harry was a 49 year old man with severe learning disabilities and profound communication difficulties living in a palliative care service unit. He had pain related to undiagnosed bowel cancer and died without receiving any treatment other than paracetamol for his pain. A learning disabilities nurse wrote that 'this man was unable to communicate his distress in a way that carers and staff could interpret.' He had the right to quality of life like any other human being except that his needs were sometimes misunderstood because he communicated them differently.

How could it be that health professionals do not always notice distress? Was this misdiagnosis due to a weakness in observational skills? Do intuition and the confidence to use it in clinical practice have a role to play in identifying the distress cues for people with learning difficulties and communication difficulties? We believe that these are important questions that need asking.

The phenomenon of caring for people with communication difficulties (PCD) experiencing distress in palliative care settings is not fully understood. And yet, learning disabilities affects 2.5% of the population in the UK (DH, 2001) with numbers expected to increase annually (Emerson and Hatton, 2008). We are all living longer and are likely to experience the effect of aging, which sadly includes an increased risk of developing dementia with its associated symptoms such as distress resulting from memory loss, mood changes and depression. Furthermore, people with learning disabilities are more susceptible to developing life-threatening illnesses than the general population (Davis, 2011). For all these reasons, Registered Nurses in Learning Disability (RNLD) and palliative care professionals will continue to be an indispensable component of an all-inclusive health system that provides care for all members of our society.

However, there is hardly any existing literature from which health and social care professionals can draw upon to either develop or broaden their understanding of caring for

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PCD and a learning disability experiencing distress particularly within a palliative care setting. Like an old fashioned tape recorder with the play button put on pause, all is quiet. It is about time to push the play button and discover what well-meaning and conscientious professionals have to say about their experiences of recognising distress of PCD and a learning disability in palliative care settings. At the University of Huddersfield a research study is currently in progress using a phenomenological approach to hear and report their unique perspectives.

As the demand for care of PCD and a learning disability within palliative care settings is growing, there is also a fundamental need to acknowledge RNLDs and palliative care in terms of the specialist care they provide for people who are distressed. It is intended that their stories of care will contribute towards meeting the demands of the changing face of palliative care, especially for PCD and a learning disability, and shout loud about how to recognising distress within this very special group of people.

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