

Commentary on “Discussing diabetes, palliative care and end of life care: choosing the right language”

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Our paper entitled “Discussing diabetes, palliative care and end of life care: choosing the right language” reports a core aspect of our research program, which focuses on older people with diabetes, palliative and end of life care for people with diabetes, and the effect of language on clear communication, that commenced in 2009 [1]. The paper shows talking about life limiting illnesses, death and planning for end of life is emotive and challenging for all concerned.

Diabetes is a slow, silent life limiting chronic disease; albeit many people with diabetes have a long life. Life with diabetes usually follows the chronic disease trajectory, which is characterised by periods of ill health and recovery. Each episode of ill health depletes reserves. Palliative care can be commenced at any time and can be used with usual diabetes care. Implementing palliative care early, leads to better outcomes [2]. Thus, recognising slow deterioration and planning for palliative and end of life care is part of holistic diabetes care.

Diabetes is a highly prevalent; globally 4.63 million people died in 2019 [3]. One person with diabetes dies every 6 seconds [4]. In Australia one in 5 people older than 75 years had diabetes in 2017-18 [5]. Thus, discussing and providing personalised palliative and end of life diabetes care is ‘gold standard.’

Prognostication about time of death is challenging and imprecise. Most people with diabetes want some idea about their life expectancy so they can ‘put their house in order’ and say their goodbyes. They are prepared to discuss palliative and end of life care, especially when their health deteriorates [1,6,7]. People generally want a ‘good death.’ For most people in our studies a good death includes dying with dignity, preferably at home with family and pets, having a say over the people present at their death, being free from pain and suffering and time to say goodbyes [6-8]. These findings are common in the literature relating to other life limiting illnesses e.g. cancer, dementia.

A key finding in our research is that people with diabetes include keeping their blood glucose in a range that avoids hypo- and hyperglycaemia as part of a good death [6]. Both high and low blood glucose cause remediable unpleasant symptoms and avoidable adverse events. To our knowledge this finding is not previously reported.

Effective communication is essential to personalised healthcare and research and palliative and end of life care, but it is often not done well. Designing care *with* consumers helps enhance care relevance and clarify acceptable language. Our research teams and expert reference groups usually include people with diabetes and family members to ensure their particular concerns are addressed. Many of these concerns relate to appropriate language and written and electronic material [1,6-8].

Our research to develop information that will help people with diabetes engage in advance end of life care planning in the current and other studies identified that they did not like the term ‘loved ones’ to refer to family members; most preferred using ‘clear words like death and dead’ rather than unclear language like ‘gone.’ They indicated unclear language can lead to misinterpretation and distress [7].

Health professionals in the current study also indicated unclear language can cause distress and

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said they used ‘gone’ to prevent distress. In fact, it emerged in our other studies and often delayed people’s acceptance of the reality of death and caused distress [7,8]. Other research shows patients prefer lay terms and were happier when the doctor adopted (mirrored) the patient’s word choice when discussing awkward topics such as sexual health [9]. Our research also shows that specific clinical communication training for health professionals enhances their capacity to have conversations with people with life limiting illnesses and document goals of care that can avoid unnecessary admissions to intensive care units [10].

Discussions with older people with diabetes and families in our studies, including the current study, suggest they find a lot of the information/handouts used to support self-care hard to read because of the language used and the way the information is designed. Handout information includes research-related information such as plain language statements (PLS) that describe what participation in research involves. This raises questions about informed consent. Most of our studies show the value of designing information to informed consent, including (PLS), with the intended participants/readers [7,8]. For example, people with diabetes, and family members helped in designing the PLS for the current study.

Many people with diabetes dislike being labelled ‘diabetic’ and find words such as ‘poor/ bad control’, ‘test’ and ‘good’ and ‘bad’ when referring to their blood glucose and HbA1c results and find these terms judgemental and negative [11]. These terms make people feel they are ‘failing,’ and are more likely to reinforce the behaviours that lead to out of range results than to change them. Sadly, inappropriate language is also used to communicate among health professionals, as one referral to a diabetes educator demonstrates [12].

The use of technology is increasing and changing the way we communicate generally, and with people with diabetes. Gentile et al. 2021 [13] suggested that although patients’ health might depend on the strength of doctor-patient relationship, we may also need to consider the clinician-technology relationship and its impact on communication and patients’ health outcomes. The current COVID-19 saw an unprecedented use of technology in health professional consultations, inter-professional meetings and ongoing education, much of which is likely to stay and have positive and negative impacts on health outcomes.

Doctors and other health professional groups’ communication skills and relationships with patients depend on many factors, including their theory of mind [14]. Theory of mind is an important cognitive skill that involves the ability to think about mental states: one’s own and other people’s. It is essential to managing complex social relationships like those that occur at emotive times such as discussing palliative and end of life care, when empathy is needed. Interestingly, reading good quality fiction enhances health professionals’ ability to relate to and empathise with ‘patients’ [14,15], possibly because it improves theory of mind [15].

Health professionals encounter real-life stories/narratives as they conduct research interviews and provide care. These stories/narratives can be patient histories, referrals from other colleagues and spoken narratives during care provision and research. Various types of palliative care interventions based on story telling are used to manage distress including personal narratives; for example, psychotherapeutic biographical writing and dignity therapy [16].

People’s narratives need to be heard and interpreted to help decide personalised care because they often encompass peoples’ values. Values are a key to the things that give meaning and purpose to the person’s life and can guide end of life care planning and goals of care. As stated, reading fiction can enhance empathy [13,14,16]. Thus, empathy is a key skill for researchers and health professionals; it might be that they should read quality fiction, as well as clinical notes and research reports! Interestingly, it is not clear whether reading quality fiction increases theory of mind; or whether people with well-developed theory of mind are drawn to stories [13,14]; this as another area for further study.

Concluding Comments

People with diabetes have many contacts with health professionals that represent opportunities to discuss palliative and end of life care e.g. during the annual clinical assessment (annual cycle of care), yet many people with diabetes do not have an advance care plan. This could partly be due to the fact that end of life care and related language was not part of the ‘diabetes dialect’ until recently. Consequently, many diabetes health professionals find it challenging to discuss death and use of euphemisms for death, as the current study shows. It is possible that building theory of mind and communication skills training could help diabetes health professionals feel comfortable to talk about end of life care planning with people with diabetes and their families.

Things we learned as researchers and health professionals

- Palliative and end of life care are part of holistic diabetes care and are increasingly being included in diabetes care guidelines.
- Narratives or stories are everywhere in health care and all types of research. They can be very informative if health professionals listen intently to interpret the story and ask good questions.
- Listening is an essential skill to communicate effectively with empathy.
- Good communication is essential to personalised care generally, and end of life care specifically. Communication involves choosing the ‘right’ words/language for the individual and knowing when and how to interrupt, if necessary.
- Most people prefer ‘clear language;’ listening to the words they use as they share their stories can help health professionals choose appropriate language to communicate with the individual.
- Communication-based clinical interventions enhance health professionals’ conversations with people with life limiting illnesses, improves end of life care planning and helps identify peoples’ values and goals of care.

Finally, this current research paper confirms our earlier work that people with diabetes are prepared to discuss end of life care, if communication is sensitive and that they prefer ‘plain language’.

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