Identity and relationships are central to the construction of patient centred care

The concept of patient centred care is now widely accepted as one of the defining characteristics of chronic disease management in the 21st century. The logic for this shift from clinician centric to patient centred care is that it provides the critical conditions necessary for patients to be activated in the management of their disease. This activation is key, given that self-management behaviours are essential in disease prevention and in optimising therapy. In addition, patient centredness is important in helping patients understand and adjust to life with diabetes, as it affords the opportunity for them to experience control and learn from their experiences.

However, the jurisdiction and meaning of patient centredness are complex. A patient centred approach has multiple meanings ranging from an individualisation of therapies to approaches that seek to engage patients in identifying their own treatment goals. In this issue of the journal we have a collection of papers that encourage us to reflect on the concept of patient centred care. Two central themes within the papers are identity and relationships.

In the paper by Ogden and Parkes, we are asked to consider whether the labels which patients are given have a stigmatising effect that may be detrimental to their engagement with their diabetes and its management. While the data did not show strong differences between labels (i.e. a ‘diabetic’ or a ‘person with diabetes’), it does make us consider how an individual might identify with their disease. Some patients will refer to themselves as a ‘diabetic’, others as ‘a person with diabetes’ or even as a partner in their disease management. The fundamental point is that in a patient centred model it should be about allowing the patient to find and express their own identity, rather than it being imposed by the health professional. Sometimes this identity may reflect a negative sense of self and patients may need help in reconstructing an identity during their experience with the disease. Hence, understanding identity and the effect of labels in health care interactions may be an interesting area for further research and inquiry. In the spirit of patient centredness, perhaps we should allow patients to choose their own labels; it is then the job of the health professional to understand and work with that choice.

The papers by Rintala and Simmons encourage us to think about the impact of different types of relationships in diabetes care. These studies highlight the importance of relationships, both informal in the context of family life and formal through organised peer based interventions. In recognising the power of these relationships, perhaps we need to expand our construction of patient centredness to include these important personal and social networks. Therefore, a patient centred approach is not patient centric: it is about understanding the person in the context of their social world and the network of relations that may either enable or inhibit their ability to adapt to life with diabetes.

Peer interactions are also important and Simmons’ report indicates that there is scope to expand organised programmes of peer support. While there is still much to be understood as to how best to develop and resource such programmes, it would seem that these are generally valued by patients. We must also recognise that there is an informal peer system already, with many patients interacting through a variety of media. As with family interactions, these can be either enabling or inhibitory.

Finally, in the report from Mehica we are reminded that the patient centred model is not universally applied and that nurses may need more training to develop the skills necessary to deliver the model. Mehica’s study of patients’ perspectives on the surgical management of foot complications highlights the need to ensure that patients’ needs are understood and addressed within the care system. While listening to patients and supporting them to make decisions are core elements of the patient centred model, it is also about a partnership whereby the professional helps the patient to identify themselves with their disease and provides appropriate assistance. This needs to operate at the system level, such that there is a high level of awareness in relation to potential patient centred issues relating to their experience of treatments and the impact of complications. To achieve this we must remember two of the things that patients value most highly – these are being listened to and given time. It is these two conditions that give the space that is essential for a patient centred approach.

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