Portsmouth Hospitals NHS Trust

drparthakar@gmail.com Follow Partha

on Twitter: @parthaskar

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THE BOTTOM LINE

Partha Kar: Changing the narrative around self-management

Partha Kar *consultant in diabetes and endocrinology*

One of the biggest challenges for any healthcare system is how to support patients with chronic disease. While focusing on the availability of healthcare professionals is understandable, this may mean neglecting the basic tenets of chronic disease management and the greater challenge that lies elsewhere.

To me, managing chronic disease well is founded on three basic principles: self-management, peer support, and access to trained professionals. We do not spend enough time and effort on the first two.

For instance, in self-management much attention is given to what the healthcare system perceives to be the best way to deliver it instead of what is actually needed or even relevant today. A case in point is education programmes in diabetes care. Until the start of the covid-19 pandemic these programmes still focused on delivering learning through face-to-face, classroom-style sessions, despite the fact that a huge range of tasks—from banking to booking cinema tickets and flights—are today carried out on smartphones in the palms of our hands.

The debate over encouraging modernisation of this cornerstone of self-management has stalled, as many simply assumed that introducing new technologies would lead to the replacement of current arrangements. In fact, the strategy for a population that varies with age, deprivation, ethnicity, and other characteristics should combine traditional and modern approaches.

The pandemic has changed the narrative. Suddenly, forced partly by policy and the need to adapt, most relevant diabetes education programmes have adopted an amalgamated approach. Examples include the rollout of digital educational programmes in type 1 diabetes through Digibete.org and the MyDiabetesMyWay app, or indeed existing providers, such as DAFNE (Dose Adjustment for Normal Eating), adapting to modern times by having a digital arm. Yet much more progress is needed. After all, the welfare of the person with diabetes should stand first, and the best education programme for any individual is the one that that person with diabetes attends and benefits from.

With peer support, the NHS does very little to facilitate this, mostly relying on the voluntary sector. As good as those organisations can be, they have their own restrictions, and the funding available to charities to support such work is limited.

A patient spends around 0.02% of their year in direct contact with the NHS for their diabetes management, if we assume four visits of 30 minutes each, leaving 99.98% of their time having to deal with the

challenges of the disease. Self-management can be tiring and tough on mental health, and a key benefit could and should be the help from peers who also deal with such issues day in, day out. Yet the NHS's focus on peer support is minimal, which isn't surprising, given the service's track record in involving patients.

What we do have is engaged communities trying to do as much as possible themselves, with the sporadic involvement of clinicians led by their personal commitment, beliefs, and desire to engage.

Again, the pandemic has shown a way forward: expanded access to non-invasive glucose monitoring, digital approaches to self-education for people with type 1 diabetes, and the establishment of networks of professionals to encourage peer support. It's not about digitalising all things but encouraging peer support and interactions, as well as improving the tools of self-management.

Preliminary data show that people with type 1 diabetes have had fewer admissions with diabetic ketoacidosis since the start of the pandemic. The reasons are likely to be multifactorial, but efforts to improve access to self-management tools and peer support may well have had some bearing.

If, as a system, we want to improve chronic disease management, we need to switch our focus from healthcare professionals to the people with the chronic disease themselves, and to providing equitable access to all three principles of self-management, peer support, and trained professionals. The pandemic has given us an opportunity to do this.

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