One in three chronic patients do not understand their illness

One in three patients with a chronic disease struggle to understand what their doctor tells them and don’t understand their own illness.

One third of patients with a chronic disease find it hard to understand their own condition and the advice they receive from their doctor or health visitor. This is the conclusion of a new study of almost 30,000 Danish people, many of whom suffer from a range of diseases, including cancer, cardiovascular disease, and type-2 diabetes.

The study is the first population-based research into how well patients with chronic illnesses engage with the health care system in Denmark. It considers how well they understand their own disease and their ability to work closely with health care staff.

The new results are published in the journal BMJ Open.

“As much as 30 to 40 per cent of patients with a chronic illness have difficulties understanding the health information available on their own disease, and find it difficult to interact with health care professionals. But in the rest of the population this is more like 8 to 20 per cent,” says Helle Terkildsen Maindal, a lecturer at the Institute of Public Health at Aarhus University, Denmark, and the lead scientist at Steno Diabetes Centre, for health promotion and prevention.

Patients of mental diseases worst hit

As many as 30 per cent of cardiovascular patients had difficulty understanding “written information”, and up to 30 per cent of diabetics said that it was “hard” or “very hard” to communicate with health professionals and to understand the information that they received. This often leaves them unprepared to cope with their disease.

The worst figures were in the case of mental illness, where as many as 40 per cent of patients reported difficulties with understanding their illness or interacting with doctors.

"Even when we adjust for gender, age, ethnicity, and level of education, there is still a gap. Chronic sufferers have a lower health literacy than the general population," says Maindal.

“A waste of resources”

Jens Søndergaard, a professor of general medicine at the University of Southern Denmark, studies the treatment of patients with chronic illnesses.

“Unfortunately, I’m not surprised by the results,” he says. “We know very well that when we give patients
information about their condition, and explain the pros and cons of their medication, there are lots of people that just don’t understand.”

The problem seems to be communication, says Søndergaard.

“What we lack is a scientific-based knowledge about how we should inform [our patients]. There is a tendency to just make new pamphlets and websites, and then make more pamphlets and websites,” he says.

“Healthcare is populated by academics who often speak a complex language. Everyone wants to get the messages out, but we just don't have the tools to do it,” he says.

The confusion is not only bad for patient health, says Søndergaard, but it is also a waste of resources to let patients slip through the net.

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Many patients suffering from chronic disease do not understand their own illness or the information that health professionals give them. (Photo: <a href=http://www.shutterstock.com/pic-131122493/stock-photo-male-patient-tells-the-doctor-about-his-health-complaints.html target="blank">Shutterstock</a>) [8]

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