Care Plans, NDTMS and TOPs: How They Can Adversely Affect Patient Care

In a GP consultation with a drug user these days I often feel that I am at a considerable disadvantage with regard to providing top quality primary care. This is because so much of the consultation has to be devoted to data collection which has no real bearing on the patient's care: 'care plans', National Drug Treatment Monitoring System (NDTMS) and the Treatment Outcome Profile (TOP).

GPs are no strangers to care planning and indeed we are natural care planners: it is an essential skill of the job. In a standard consultation I take a history, examine the patient, take steps along the diagnostic pathway in my own mind and reframe these in a manner accessible to the patient in order to agree a joint plan for the way forward and a back-up in case things do not go according to plan. Often this may include liaison with other agencies and workers. A brief note sums this up to set the baseline for the next consultation, in which a further step will be taken along the diagnostic and treatment pathway. This is care planning. It is a skill which applies equally with patients who have cancer, childhood illnesses or any other condition.

With a drug using patient this process is not so simple. I am faced first with a data collection template which furnishes the NDTMS return. Next I have to complete a 'care plan' at predetermined intervals, which bears little relation to the real care planning process described above. More recently we have TOPs: the additional task of repeatedly completing a questionnaire of sensitive data which will be used for monitoring purposes unrelated to the individual patient's care.

NDTMS has developed gradually as a replacement for the old notification system for addicted patients. However, it seems that smuggled in on the back of the simple notification of patients with addiction problems is a growing host of other data items collected for monitoring purposes.

No doubt this collection is politically important. However, the 3 monthly collection of data has made it so onerous that many GPs need the help of shared care workers or data officers paid for by DATs who have to spend significant amounts of time collecting this data set.

In addition to this there is now the regular burden of three-monthly face-to-face data collection for TOPs. Like most GPs, I am intensely interested in the evidence base for treatment outcomes and in carrying out the peer-reviewed and ethically approved research that is needed to produce these. The outcome measurements of TOPs, however, must always be in doubt: first because the untrained data collectors are placed under such intense pressure to collect the data from patients (whose consent to this collection and storage of their personal data is largely taken for granted) and secondly because the data collectors in this situation have a vested interest in the outcomes. This will become increasingly the case as the results of the monitoring begin to be used to evaluate performance and to compare services so that services may see their funding in the balance.

For these reasons the data quality of TOPs risks being extremely poor and would be unlikely ever to stand up to the scrutiny of peer review. In recent discussions with GPs who were filling in TOPS forms themselves, one commented that he "didn't have time to fill it in during the consultation and waited and did them all together at the end". Another said that he "simply handed it to the patient and got them to fill it in" and one commented that the key workers were sometimes driven to filling the forms in over the phone.

However an even more important issue is that TOPs can actively detract from patient care, even when the GPs are not spending valuable consultation time filling them in themselves. One General Practitioner with Special Interest (GPSI) commented that he had personally never seen a TOP form, but the key workers working with his service never had time now to do any real key working with patients who needed it because they spent their whole time chasing up all the patients every three months to fill in the TOPs forms. Numerous others echoed this.

Excessive data collection requirements can only be a barrier to GPs wanting to treat drug using patients, and the burden of overlapping data collection for this group of patients needs to be addressed urgently. It is ironic that drug users are often among the most needy of our patients and require more of our attention and time than non-drug users, but because of the excessive burden of form-filling and paperwork for these patients the opposite is likely to happen.

In an increasingly data protection conscious world it can surely only be a matter of time before the patients themselves question this process and the need for so much personal data to be collected about them for purposes unconnected to their personal care. It is perhaps only because so many of our patients are vulnerable and disadvantaged that this has not already been challenged. Meanwhile we are in danger of losing the genuine consultation in a sea of box-ticking.

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