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What do the patients want?



The consumer model of health service delivery has made allusion to the primacy of the patient's wishes required content in any policy statement or guidelines. That makes those wishes contested territory; commentators committed to certain treatment goals will appeal for validation to what is seen as the ultimate authority – the patient. In turn that makes research on patient perspectives critical, and sometimes also contested.

Is abstinence the overriding aim?

For addiction treatment in the UK, the prime example came from Scotland, where researchers from the DORIS national treatment evaluation study have differed over the implications of their findings. It started with the "surprising" finding that 57% of Scottish drug treatment clients selected abstinence as their sole goal for changing their drug use. For the lead author it was a sign that we have failed to match patients' ambitions and instead prioritised harm reduction. But a colleague saw it differently. It was, she said, unclear what patients meant when they ticked "abstinence/drug free" in response to the question, "What changes in your drug use do you hope to achieve by coming to this agency?" Did they mean free from all drugs, or just the one(s) causing them problems? Free now, or some time in the future? Was this an aspiration, rather than what even the patient would claim was a realistic goal? It might also be asked whether the finding really was "surprising"; 44% of patients were starting drug-free and/or explicitly abstinence-based treatments and the same proportion were in prison, where abstinence would normally have been the only sensible objective. Rather than a surprising mismatch, the paper can as easily be read as showing patients' objectives match those of the treatment they are entering and the constraints of the setting.

Nevertheless, the seeming contrast with the supposed finding that just 3% of Scottish methadone patients emerged from treatment drug-free was headlined as proving treatment fails patients, and used by politicians to justify what the media described as a "Cold turkey plan for Scots addicts." Their case was sharpened by the further contrast with what was portrayed as a corresponding figure of 25% drug-free after methadone treatment in England.

At best these extrapolations were sloppy, at worst, deliberately misleading. The iconic "3%" figure came from a DORIS report which documented the progress 33 months later of 695 (all who could be reinterviewed) out of 1033 problem drug users who started treatment in 2001 and 2002. Read our analysis, and you will see that it was based on patients who had entered methadone programmes only after leaving their first treatment during the study period. That makes it particularly pertinent that in DORIS as in other studies, over the years patients rarely confined themselves to a single modality, complicating the assessment of just what it was which led to the eventual outcomes. It becomes a matter of choice whether such patients' progress is attributed to the initial non-methadone programme, whether transfer to methadone is seen as indicating the initial treatment had failed and their progress was due to the follow-on care, or whether the whole treatment journey is seen as the active ingredient.

In contrast, the 'corresponding' 25% figure for England more conventionally related to the *initial* treatment – enough to invalidate the comparison. Also the definition of abstinence in Scotland meant patients must have been free both of any illegal drug and of prescribed methadone. In England, they could have been on methadone and/or using cannabis. Scottish apples were being compared with English pears, and then with the supposed ambitions of Scottish patients, which in reality were not at all clear.

Ambivalence about taking medication in the form of a desire to be free from having to take the pills or concern over their side-effects and efficacy is commonly observed in long-term prescribing, not just for opiate addiction, but for chronic physical and psychiatric conditions. Such is the scale of this problem that it is a recognised and major concern for clinicians, who fear it leads patients to decide not to take or to prematurely cease or cut down medication, to the possible detriment of their health. That opiate users prescribed methadone or other substitutes share this ambivalence should not be a surprise, especially given the unusual burdens the treatment often entails, such as supervised consumption and daily attendance, the stigma attached to regularly consuming opiate-type drugs (even legally prescribed), and the fact that the treatment marks the patient as an 'addict'.

We just want to be normal

Though important, misreading of the DORIS findings should not obscure the fact that, however the individual defines it, stopping use of some drugs (especially those so problematic that they have driven them to seek help – in the UK, normally heroin and/or cocaine) is a common goal, and that for substitute prescribing patients, it often extends to eventually being free of legal substitutes too. Surveyed in 2007 – but specifically about their long-term goals in respect of drug use – 81% of drug treatment clients in England who used heroin wanted to stop doing so; for cocaine, the figure was 73%. But only minorities wanted to cease using cannabis, alcohol or benzodiazepines, and 51% methadone. Given the question, fewer would have wanted to stop their methadone right now or in the next weeks or months.

Beyond drug-focused goals is broader recovery from a life diminished and distorted by excessive and



unificating reliance on psychoactive substances. When in 2014 problem drug and alcohol users in and out of treatment in England were asked about their views on recovery, none of the drug-focused criteria identified by senior staff in treatment services received widespread endorsement, and whether being in opioid substitution treatment was consistent with recovery was a "divisive issue with no consensus in any group." Instead, participants "repeatedly argued that recovery meant 'being normal' and 'living life like everyone else'." The route to 'normality' meant neither being like each other or like other people but was individually defined, and included the usual vulnerabilities and faults. Rejected were the "superhuman" criteria apparently requiring these troubled individuals to become more worthy and better balanced than many people who have never had a substance use problem.

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