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▶ A good quality of life under the influence of methadone: a qualitative study among opiate-dependent individuals.

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De Maeyer J., Vanderplasschen W., Camfield L. et al. Request reprint

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Opiate dependent methadone patients in Belgium give their own accounts of what for them constitutes a good quality of life. Generally they want what other people want: a meaningful, independent life and supportive relationships. Methadone creates the preconditions for such a life at the same time as it limits its achievement.

Summary Despite a shift from objective to more subjective outcome measures in both general and mental health care, attention to consumers' perspectives is still limited in the field of addiction research. Typically, evaluation studies start from a unilateral focus based on the norms and values of society, instead of basing their measures on drug users' personal experiences. In particular, until the 1990s addiction research gave only limited attention to quality of life, though since 2000 interest has grown extensively.

The concept of 'quality of life' is vague and inconsistently used. Rather than a fixed and universal concept, several authors have demonstrated the importance of the individual's own ideas of what for them constitutes a good or bad quality of life. But like other marginalised groups, the perspectives of drug users on what constitutes quality of life have largely been ignored; outcomes in quality of life studies are mostly measured according to what is important to health care professionals rather than to the users themselves.

Similarly, there is little qualitative research on clients' perspectives of the impact of methadone on their functioning and in particular on quality of life. If one of the goals of methadone treatment is to improve the quality of life of the patients, then it will be important to involve clients in participatory research on quality of life and on the influence of methadone treatment on their daily lives, so that they can be part of the process rather than spectators.

To help fill this gap, in 2008–9 the featured study conducted in-depth interviews with 25 patients who started methadone treatment in the region of Ghent in Belgium from 1997 to 2002. They were sampled from and broadly representative of the 154 participants in the parent study who agreed to be interviewed (only five did not agree). The aim was to select people currently in and out of treatment with different levels of heroin use and social and personal characteristics which might influence their quality of life. Typically they were single men in their 30s. Two thirds were in methadone treatment, nearly half had used heroin in the past month, and three quarters had injected, but generally not in the past month.

The aims were to identify what for opiate-dependent individuals constitutes a good quality of life and the impact of methadone on those aspects their lives. By focusing on positive aspects of their lives, the study started from a strengths-based standpoint rather than taking a problem-oriented approach. Apart from being asked to address these two questions, participants were free to narrate their personal experiences in their own ways. The resulting interview transcripts were analysed to identify themes and sub-themes relevant to the issues addressed by the research.

Main findings

From the analysis emerged five main themes which formed important aspects of a high quality of life for these opiate-dependent individuals: having social relationships; psychological well-being; having an occupation; being independent; and having a meaningful life. Each is explored in more detail below.

Social relationships were universally mentioned. Frequently the presence of a good friend, children, or a supportive, caring partner characterised times with the highest quality of life. Being integrated in and supported in society, even if only in their immediate circles, had a positive impact, engendering feelings of acceptance and respect. The presence of like-minded people often created a feeling of solidarity and a sense of belonging. Maintaining relationships also involved feelings of responsibility and taking care of someone else, enhancing self-esteem.

The stigma of being on methadone (for some experienced daily when having to take their methadone at a pharmacy) was frequently said to impede the formation of such relationships and social integration in general. Family and employers see methadone as a drug rather than a medicine and distrust people who use it. For other participants, taking methadone was a personal secret they carried with them because they feared the social consequences of admitting methadone use. Nevertheless, methadone helped opiate-dependent individuals take responsibility for their children, one of the most important components of their quality of life, and promoted social integration by enabling them to function normally and operate in society. Often, those participants kept their methadone use secret.

Psychological well-being – 'feeling good about yourself' – also characterised the best periods in their lives since they started taking methadone. These feelings often arose when individuals were able to become free of illegal drugs or achieve something in life. Increased self-respect also resulted in more intensive self-care. During these periods interviewees also felt an inner calm and emotional stability previously transiently achieved only by using drugs.

On these feelings methadone treatment had a dual impact. The emotional levelling impact meant some interviewees felt they were not fully enjoying life, but this also meant they no longer experienced severe negative emotions, while methadone's ability to substitute for heroin enabled them to experience feelings not focused only on obtaining drugs. For some methadone treatment's levelling effect enabled them to deal with other emotional problems affecting their quality of life. Several said it meant they were no longer dominated by the direct consequences of their drug use such as financial problems, looking for drugs, or being 'sick' due to withdrawal symptoms.

Having an occupation – work, hobby or training, or just something meaningful to do – was prominent in stories about times participants experienced their highest quality of life. It avoided boredom and filled their days, taking their minds of using drugs. Most participants were heroin-free during the time their quality of life was the highest, but this was only a prerequisite for a good life – it did not in itself constitute a good life. A replacement for their drug use was essential to actually enhancing their quality of life, not only because it gave them something to do, but also because of the meaning attached to that occupation. For example, having a job resulted in higher self-esteem and a positive self-image; participants felt responsible and that they were contributing to society instead of being 'a lazy junkie'.

Methadone' role was most noticeable for making it possible for the individual to work, though side-effects often restricted the jobs they were able to do.

Being independent was one of the most important components of a high quality of life – in the sense of no longer being dependent on opiates or other drugs, being financially independent, and not reliant on another person for their sense of well-being. In these periods they felt they had gained control of their lives and were standing on their own feet.

Again methadone had a dual impact – positive because it aided financial independence and meant they were no longer dependent on illicit opiates, enhancing control over their heroin use. However, at the same time a new dependence on methadone was created – one difficult to withdraw from and entailing lengthy practical and institutional dependence on treatment services, restricting personal freedom. Moreover, for some taking methadone signified that they were unable to leave their pasts behind and were still part of the drug scene. Take-home doses of methadone were mentioned as a way to improve quality of life and control methadone dependence. Finally becoming methadone-free was seen as a major victory in life.

A meaningful life was associated with settling down, the security of a family and striving for stability in life. Enjoying small, ordinary things was frequently mentioned. Purposeful living is strongly connected with having daily activities that a person is interested in, that make them feel useful, and feel they actually mean something in this world. Having goals and prospects was a significant sub-theme, extricating participants from a vicious circle of hopelessness and acting as a vehicle through which to further develop one's personality and discover new things.

Methadone promoted a meaningful life by enabling stability, security, and freedom from the roller coaster of illicit drug use, providing a platform from which to deal with problems and think about and plan their lives from a more long-term perspective. By stabilising lives, it can also directly help achieve those goals – pass exams, complete

courses, get jobs. Nevertheless, several participants said methadone was limited in the degree to which in itself it could help them construct a meaningful life, acting purely as a substitute for heroin. They cited the importance of psychosocial counselling. For most, a meaningful life involved being drug *and* methadone free, but methadone was seen as a stepping stone in this life-long process.

Implications of the findings

Based on this in-depth study, among opiate-dependent individuals, periods of a high quality of life were characterised by supportive and caring relationships, having an occupation, high psychological well-being, being independent, and a meaningful life. The availability of supportive relationships was been one of the major themes, indicating that methadone treatment services should pay attention to their patients' social lives alongside their psychological functioning.

The importance of psychological well-being and feeling good about yourself echo findings in mental health research – not surprising, given how common psychiatric co-morbidity is among opiate-dependent individuals. It demands attention to the common prejudices which lead to people being stigmatised and indicates the need for integrated drug dependence and mental health treatment.

Purposeful living – feeling useful and being able to give something back to society – was strongly connected with personal development and growth. Creating possibilities for personal development improves quality of life and means patients are more positive about the benefits of methadone treatment. Eluding concrete formulas, these issues have received limited attention in clinical practice. Nevertheless, interventions which address goals and meaningfulness in life and counter the discrepancy between how things are now and the patient's hopes and expectations are likely to improve quality of life.

The urge for independence was another key finding in this study which has previously received little attention in the substance use field but is commonly cited in (mental) health care research. Ways to promote feelings of control and independence include financial aid and helping patients find work through vocational therapy.

Notably, these themes are universally relevant not just to people with opiate dependence, but also to mental health patients and the general population. This generic character is not surprising since opiate users also fulfil diverse social roles and desire 'normalcy' in their lives. Nevertheless, interpretations of those themes and the factors which obstruct or promote them are to a degree specific to marginalised opiate-dependent populations, including social isolation, psychological problems, and stigma as a result of a drug using lifestyle. Staff working with these populations should be sensitive to the impact of these, often long-lasting limitations that are beyond the direct consequences of drug use. They mandate a holistic, continuing care approach such as strengths-based case management, which builds on a person's strengths and abilities rather than the pathology-oriented practice dominant in substance use services.

From the opiate user's perspective, a good quality of life had little to do with strictly health-related issues. Focusing only on the pharmacological and health consequences of methadone treatment and ignoring its influence on self-experienced quality of life gives a one-sided representation of this intervention. Several of the themes that from the individual's perspectives were relevant to a good life were distant from current treatment

goals. Methadone is a social as well as a pharmacological intervention.

Participants were ambivalent about the impact of methadone on quality of life. Positives included gaining control over one's life and daily functioning and no longer being 'sick' when heroin was unavailable, creating the preconditions for engaging in activities (such as training, finding a job, looking after children) which enhance quality of life. On the negative side were severe withdrawal effects on stopping methadone, stigmatisation and dependence. Institutional and practical as well as pharmacological dependence restrict freedom and are often accompanied by anxiety about a chronic dependence on methadone which (given that dependence is what they wish to escape from) strongly limits feelings of overall well-being. Dependence is often aggravated by long-lasting stigmatisation and discrimination which impede daily functioning and the development of a positive identity. These negatives can be mitigated by making individuals active participants and empowered decision-makers in their treatment and by helping them to gain control over their lives.

In general, opiate-dependent individuals consider methadone maintenance a transitional phase to tide them over during a certain period in their lives. Most participants in this study wanted an opiate-free life without methadone dependence. Harm reduction, and methadone treatment in particular, can be a vital link in the recovery process. Rather than being in opposition, harm reduction and abstinence-oriented approaches could form part of a continuum which enhances quality of life from a long-term perspective. Nevertheless, for many abstinence might not be realistic or even desirable; for them, substitution treatment can be a life-long aid in enhancing quality of life and gaining control over drug use and their lives.

For the opiate users in the study, becoming free of illegal drugs was a precondition for rather than the essence of a high quality of life. This suggests that nurses in methadone programmes should go beyond dispensing methadone to offer psychosocial support and positive interactions with clients. Especially among non-specialists, these aspects of their roles are hindered by mistaken stereotypes of individuals with dependency problems and preferences for rapid cure approaches which fail to acknowledge the chronicity of drug dependence. Besides drug and alcohol education, supervision and role support are necessary to enhance nurses' personal well-being, professional skills and attitudes and create a supportive environment to work with this challenging population.

It should be acknowledged that the findings of this exploratory study may not be generalisable to other opiate-dependent populations or other drug users.

FINDINGS The implications of this study could hardly be more relevant to current debates in the UK about reorienting treatment to a broader recovery agenda and the role within that of entering, being in and leaving methadone maintenance treatment. For treatment services it poses the issue of the limits of their remits. Opiate addiction treatment services can and do reduce or eliminate heroin use, but this is merely the platform for constructing a better life, not a better life in itself. Is it the role of services to go beyond treating opiate dependence to help patients towards a fulfilling life? Is this an essential relapse-prevention task needed to prevent recurrence of illness in the form of heroin dependence, or a role not for medical services, but for the patient in relation to the wider community – family, civil society, neighbourhoods, churches, local authorities, cultural centres, educational and training institutions among others? If treatment services

take on these roles themselves or take on the coordination of broader life enhancement services and relationships, where does their responsibility for the patient end, and when does the patient stop being a patient? Arguably the extension of treatment support beyond the end of illness is itself a limiting dependency. What of patients for whom personal development and a fulfilling life as generally accepted are not on their agendas, but who still seek the support of treatment services as a survival aid, respite, and support in living their own still socially deviant lifestyles? Are they still to be welcome in 'recovery-oriented' services? These debates are current in UK addiction treatment circles and yet to be resolved.

It should be noted that the population of users in the featured study were mainly in their thirties. Nearly a third of the opiate dependent users facing British clinicians are 40 or older. At these ages strictly health-related problems may be more prominent constituents of and/or limitations on achieving a satisfactory life.

Some of the same authors have conducted the first systematic review of research on the quality of life of opiate users, It concluded that quality generally improves on entering substitute prescribing treatments, but that few studies have assessed what counts as a good life from the point of view of the patient.

To make it easier to search for this and other quality of life studies, in its free-text search facility Findings treats 'quality of life' as a single phrase, avoiding the retrieval of studies which simply have these three words in the text, but not as a single phrase. Enter the words 'quality of life' (without the quotation marks) in the 'ALL of these words' box to search for studies related to this concept. Add other words (eg, heroin) to narrow the search.

Thanks for their comments on this entry in draft to Neil McKeganey. Commentators bear no responsibility for the text including the interpretations and any remaining errors.

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