

Exploratory Study on Drug Users' Perspectives on Quality of Life: More than Health-Related Quality of Life?

Jessica De Maeyer · Wouter Vanderplasschen · Eric Broekaert

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Abstract In drug treatment outcome literature, a focus on objective and socially desirable indicators of change (e.g. no drug use) has predominated, while outcome indicators that are important for drug users themselves (e.g. quality of life, satisfaction with treatment) have largely been neglected. Nonetheless, Quality of Life (QoL) has become an important concept to evaluate effectiveness of treatment in mental health care research and disability studies. Given the almost exclusive focus on Health-related Quality of Life (HRQOL) in substance abuse research and the neglect of clients' perspectives in this field, we explore in this study the concept of QoL as perceived by drug users. Focus group discussions ($n = 9$) were organised in various treatment settings and community services for drug users in the region of Ghent, Belgium to identify important dimensions of QoL and their interpretation by drug users. Data were clustered and analysed based on the theoretical framework of Robert Schalock (Quality of life. Volume 1: Conceptualization and measurement, 1996). The domains 'personal relationships', 'social inclusion' and 'self-determination' were discussed most frequently by the participants. They stressed the importance of a supportive social network in particular. It can be concluded that QoL is not primarily associated by drug users with health and it involves much more than the aspects typically represented in measures of HRQOL.

Keywords Quality of life · Drug use · Substance abuse treatment · Focus groups · Health-related quality of life · Drug users · Participative

1 Introduction

Substance abuse is an important public health problem that directly affects millions of people worldwide and has serious economic, health and social consequences. For example, in the US, the lifetime prevalence of substance use disorders is estimated to be around 18% (Anthony and Chen 2004), while rates of alcohol and illicit drug use among the adult

J. De Maeyer (✉) · W. Vanderplasschen · E. Broekaert
Department of Orthopedagogics, Ghent University, H. Dunantlaan 2, 9000 Ghent, Belgium
e-mail: Jessica.DeMaeyer@UGent.be

population in the EU vary between 4 and 12%, and 1 and 8 per thousand respectively (EMCDDA 2007; WHO 2004). Given the dramatic social impact of substance abuse, there has been an almost exclusive focus on objective and socially desirable indicators of change (e.g. no drug use, no criminal activities, employment), while other (functional) outcome indicators that are important for drug users themselves (e.g. quality of life, satisfaction with treatment) have largely been neglected (Fischer et al. 2001a, b). This reflects the utilitarian perspective on substance abuse treatment outcome research that has predominated during the last 25 years, concentrating on public nuisance, social and economic costs, cost-effectiveness and societal benefits (Barnett and Hui 2000; Fischer et al. 2005). Few studies have focused on the question whether these outcomes are congruent with the perspectives of drug users themselves (Fischer et al. 2001a, b). Unsurprisingly, there is often little relationship between socially desirable outcomes and experienced Quality of Life (QoL) (Foster et al. 2000).

2 Aims of the Study

The aim of this study is to explore the concept of QoL as perceived by drug users. This is necessary due to the lack of attention to QoL in substance use research, the almost exclusive use of Health-related Quality of Life (HRQOL) as an outcome measure, and the neglect of clients' perspectives. According to Fischer et al. (2001a, b), there is an urgent need to elaborate a conceptualisation of QOL, based on drug users' experiences and perspectives (Farquhar 1995). This will not only extend the scope of research on the effectiveness of treatment, but the participation of clients in outcome research may itself have a positive influence on their personal well-being (Schalock and Verdugo Alonso 2002).

In this article, we want to address the lack of information about drug users' perspectives on QoL by approaching it as a sensitizing concept; by listening to the stories and experiences of drug users, we want to discover what QoL means from their point of view. The assumption that quality of life is a dynamic concept (Allison et al. 1997) requires that researchers begin by listening to individuals' own voices and opinions to understand how they perceive QoL. This paper is structured as follows: first, we focus on available QoL-research among substance abusers, explore the concept of QoL in general and identify problems arising when measuring QoL. Then, we outline the research methodology and describe the study participants. We report the main findings from this study, which are illustrated by respondents' quotations. Finally, the results are compared with findings from the fields of disability studies and mental health care and between-group differences are discussed.

3 Background

Substance abuse is increasingly recognized as a chronic, relapsing disorder, which is nonetheless recoverable and so requires a continuing care perspective rather than an episodic treatment approach (Brindis and Theidon 1997; McLellan et al. 2000). Treatment outcome research has primarily focused on abstinence and the reduction of drug-related problems, while relatively few studies have been published concerning QoL among drug users (Torrens et al. 1997; Smith and Larson 2003). Fischer et al. (2001a, b) suggest that this might have to do with the fact that drug users are often seen as "undeserving patients", who are responsible for their own problems. However, instruments for measuring QoL

(e.g. the Lancashire Quality of Life Profile, WHOQOL) provide information that is not included in traditional diagnostic and evaluation tools for measuring substance abuse such as the Addiction Severity Index (ASI) or Maudsley Addiction Profile (MAP) (Giacomuzzi et al. 2005; McLellan et al. 2006; Smith and Larson 2003). They also give a comprehensive view of people's situations, not only focusing on problems and disabilities but also looking for strengths and resources (Maremmanni et al. 2007; Saleebey 1996).

Most studies that have assessed QoL among substance users remain limited to aspects of health-related QoL (HRQOL) (De Jong et al. 2007; Garg et al. 1999; Rudolf and Watts 2002; Torrens et al. 1997), despite the fact that several authors have demonstrated that QoL is a broader and therefore more useful concept (Boevink et al. 1995; Cummins 2005; Schalock 1996). HRQOL is a subjective measure of people's mental and physical health and its influence on their functional status (Farquhar 1995; Millson et al. 2004; Mooney 2006). It mainly addresses what a person can or cannot do anymore (e.g. the SF-36 Health Status Questionnaire).

Research has shown that alcohol dependent persons generally have a lower QoL as compared to the general population (Smith and Larson 2003; Stein et al. 1998), but this improves once alcohol consumption is reduced (Foster et al. 1999). Other authors have also demonstrated a negative effect of psychotropic drug use on QoL (Stein et al. 1998; Ventegodt and Merrick 2003), but it remains unclear whether this can be attributed to the drug use itself or to the negative life events that may have induced drug use. Drug users' scores for physical health are similar to other populations with chronic problems, but their mental health scores are usually much lower. This is associated with the strong co-morbidity between substance abuse and psychiatric symptoms (Millson et al. 2004; Smith and Larson 2003). Factors that influence drug and alcohol users' QoL negatively are heavy alcohol use and infectious diseases (Costenbader et al. 2007; Kalman et al. 2004). However, there is no clear evidence about the direct impact of drug use on clients' QoL (Costenbader et al. 2007). Substance abuse treatment seems to affect drug users' QoL positively, especially during the first 3 months of treatment (Senbanjo et al. 2006; Torrens et al. 1997), but these effects tend to decrease over time (Giacomuzzi et al. 2006; Habrat et al. 2002).

3.1 The Concept of QoL

QoL is an overarching concept, which has often been applied in health care research (Padaiga et al. 2007), particularly in the fields of disability studies and mental health care (Masthoff et al. 2005; Schalock 2005). Nevertheless, there is controversy over the meaning of this concept, and there is no consensus about its definition (Carr and Higginson 2001; Fischer et al. 2001a, b; Moons et al. 2006; Taillefer et al. 2003). Various professions create their own interpretations, with little resemblance and much fragmentation in-between disciplines (Farquhar 1995; Rapley 2003). Nonetheless, there is a growing recognition of QoL as an important indicator for the impact of treatment, the need for health care, the evaluation of interventions and for cost-benefit analyses (Allison et al. 1997; Carr and Higginson 2001; Foster et al. 2000; Giacomuzzi et al. 2003; Oliver et al. 1997; Torrens et al. 1997).

Two approaches to QoL are usually distinguished (Noll 2000; Zautra and Goodhart 1979): objective, using objective indicators to measure the concept; and subjective, where the perspective of the person is taken into account. The objective movement describes QoL using social indicators that refer to external conditions (e.g. health, housing) based on agreed standards (Schalock and Verdugo Alonso 2002). This approach is particularly

useful for determining the QoL of the general population, but less appropriate for measuring someone's unique, individual QoL. The subjective approach—based on psychological indicators—allows assessment of people's personal perspectives on their lives (Zautra and Goodhart 1979). In general, there is a poor correlation between objective and subjective measurements of QoL (Allison et al. 1997; Cummins 2000; Edgerton 1996; Foster et al. 2000). Only when objective QoL is very low can a clear correlation can be observed between objective dimensions and their subjective counterparts, the so-called 'homeostatic defeat' (Cummins 2000). Homeostasis assumes that subjective QoL is actively managed by a homeostatic model in which people are satisfied if their life conditions are within a certain range (Mellor et al. 2003). A certain cut off-point for subjective well-being exists, and people usually return to their baseline level of well-being.

Most authors agree that QoL is influenced by both objective and subjective criteria (Cummins 2000; Romney et al. 1994), but QoL is mainly determined by the perception of the individual (Schalock and Verdugo Alonso 2002). Blumer (1969) distinguishes between QoL as a 'definitive' concept and a 'sensitizing' concept. A definitive concept starts from a clear definition, in contrast with a sensitizing concept that provides a frame of reference and suggests a direction along which to look (Blumer 1969). When QoL is regarded as a sensitizing concept, people's subjective experiences and feelings are the primary focus of research (Fischer et al. 2001a, b; Foster et al. 2000; Taylor and Bogdan 1996). Consequently, QoL may vary substantially between individuals and will be influenced by someone's specific life situation (Farquhar 1995; Taylor and Bogdan 1996). Some dimensions in life (e.g. physical health) will have a universal character, but these dimensions can vary between individuals and cultures (e.g. the perception of substance abuse among diverse ethnic minorities as a disease, moral weakness, evil spirit). Moreover, factors influencing QoL are dynamic and can change over time, including a shift of focus and priority (Allison et al. 1997; Carr and Higginson 2001; Foster et al. 2000). One of the biggest challenges in measuring QoL is trying to capture the uniqueness of this concept for each individual (Padaiga et al. 2007), which means that it is not always desirable to start from an objective standard of QoL. Many standardized instruments start from professionals' definition of what they think is important for a good QoL and are not based on clients' or patients' own life experiences (Gilbert 2004). This might result in a "tyranny of quality" (Goode and Hogg 1994) when QoL is conceptualised in such a structured way, that it ignores individual experiences. Idiographic assessment that takes into account the uniqueness of an individual and highlights the distinctiveness of each case is therefore advisable (Carr and Higginson 2001; Taylor and Bogdan 1996).

3.2 Measuring QoL Among Substance Abusers

Methodological problems arise when we want to compare outcomes from various studies, as different instruments (e.g. Injection Drug User Quality of Life (IDUQoL), Quality of Life Interview (QOLI), SF-36) have been used to measure the concept of QoL among drug and alcohol users (Ventegodt and Merrick 2003). The theoretical basis of most instruments for measuring quality of life in this population is often weak or non-existent and the psychometric properties can be poor (Taillefer et al. 2003). Instruments for measuring QoL among the general population may not be specific enough for drug users, and QoL-questionnaires for other populations (e.g. people with other chronic illnesses) may not be applicable. Up to now, little is known about how drug users perceive the concept of QoL. The available instruments (e.g. the generic Nottingham Health Profile) have been conceptualized and developed by professionals, without input from drug users themselves,

their families or caregivers (Fischer et al. 2001a, b). A useful strategy to reduce this gap is to give clients the opportunity to prioritise various domains of QoL, as the importance of a specific domain may vary from individual to individual, dependent on their values and experiences (Carr and Higginson 2001; Fischer et al. 2001a, b). Nevertheless, this method still does not change the fact that the components of QoL are established by professionals (Carr et al. 1996).

Drug users' voices are seldom reflected in the voluminous literature about substance abuse (Fischer et al. 2001a, b), even though such studies present a different perspective from counsellors' views or 'objective' measurements (Brun and Rapp 2001; Vanderplasschen and De Maeyer 2007). In other areas, e.g. mental health, cancer, asthma research, increasing attention is given to clients' perspectives about the treatment they have received and about their life in general. Drug users have not been seen as important sources of information in substance abuse research—rather as passive individuals—and their perspective is a missing link in the literature (Brun and Rapp 2001; Drumm et al. 2003; Hunt and Barker 1999). Saleebey (1996, p. 301) states that it may be one of the typical characteristics of oppressed or marginalized populations to have “one's stories buried under the forces of ignorance and stereotype”. Still, drug users have their own opinions and preferences about the type of support they need (Hser et al. 1999). Their perspectives should be included as part of treatment outcome research, rather than focusing on the implications for the community and society as a whole (Hunt and Barker 1999).

4 Methodology

In order to identify how drug users perceive the concept of QoL and to explore important influencing factors, we used a qualitative research methodology. Qualitative methods are most appropriate to focus on individuals' subjective experiences (Ager and Hatton 1999). They are necessary to gain more insight into the various mechanisms that drug users have established to cope with their lives and the constraining factors (e.g. juridical conditions) associated with it (Kaplan and Verbraeck 2001). Moreover, such methods are often most suitable to enter the world of 'hidden' or 'hard to reach' populations, such as substance abusers (Power et al. 1996).

4.1 Sample

Between September and November 2007, we organised nine focus group discussions in various treatment settings and community services for drug users in the region of Ghent, Belgium. In total, 67 individuals were involved in the focus groups, 53 men and 14 women. Some of the respondents were still using drugs (in a controlled way), others followed a type of substitution treatment, while some were not using drugs any longer. Table 1 provides an overview of the characteristics of the 9 focus groups, including the setting and the number and age range of the participants.

4.2 Procedure

Focus group discussions are a method to bridge the gap between the 'ivory tower' of the researcher and the real life of the participants (Morgan 1998). Focus groups can provide information that cannot be collected with more traditional data collection methods such as surveys or interviews (Kitzinger 1995). In addition, focus groups include the process of

Table 1 Characteristics of project focus groups

| Name and number of the focus group | Type of setting | Number of participants | Age range |
|------------------------------------|--|------------------------|-----------|
| 1. Advocacy group | A (self-)advocacy group of drug users striving for equal rights | 6 | 37–52 |
| 2. Street corner work group | A street corner work program for drug users who are often homeless and not in contact with ‘regular’ treatment | 6 | 25–56 |
| 3. Methadone treatment group | A methadone clinic for psycho-social and substitution treatment of opiate dependent persons | 4 | 25–48 |
| 4. Detoxification group | A crisis and detoxification centre for drug users | 8 | 20–31 |
| 5. Psychiatric treatment group | A treatment-unit for drug users in a psychiatric hospital | 8 | 22–46 |
| 6. Therapeutic community group | A long-term drug-free residential program for drug users | 9 | 20–30 |
| 7. Half-way house group | Supported living environment for drug users who have finished the residential phase of the therapeutic community program | 11 | 22–38 |
| 8. Prison group | Drug-free day program for drug users in prison | 10 | 21–45 |
| 9. Prison group | Drug-free day program for drug users in prison | 5 | 22–34 |

‘sharing and comparing’ between respondents and group interaction is part of the method (Morgan 1998). There are some issues to consider in conducting focus group research which are discussed at the end of the paper, in the section on limitations of the study. In this study, focus groups were used to identify important dimensions of QoL and their interpretation by drug users. On average, focus groups lasted for about 90 min, and the average number of participants was 7. Participation in the study was encouraged by providing respondents a voucher of 10€ for the local supermarket as a compensation for the time invested. All focus group discussions were led by the principal author of this article, who was assisted by a research assistant for the practicalities.

4.3 Analysis

All focus groups were audio-taped and transcribed verbatim. The transcripts were read several times by the researcher and six Master-students of special education from Ghent University. Data were coded in MAXQDA—a statistical program for content analysis—in order to identify the most important themes discussed by the participants. The methodological aim of this coding is primarily to identify patterns in social regularities and to understand them, what Kuckartz (1998) calls ‘Fremdverstehen’ (understanding the other). The six students—who worked independently in pairs—were familiar with the research subject and coded the text segments. Afterwards, their codings were compared with those of the researcher. In case of disagreement, codings were discussed until a consensus was reached in order to increase the reliability of the coding process (Vandeveldt et al. 2003).

We chose to cluster and structure the focus group data based on the theoretical framework of Schalock (1996), who conceptualised QoL as a multidimensional concept including 8 domains: (i) personal development, (ii) self-determination, (iii) rights, (iv) interpersonal relations, (v) social inclusion, (vi) emotional well-being, (vii) physical well-being and (viii) material well-being. As Schalock’s conceptualisation of QoL is a broad,

multidimensional and sensitizing concept that is widely accepted in the field of disability studies, we wanted to see if this framework is also applicable among drug users. The QoL-model developed by Schalock (1996) shows many similarities with indicators used in the field of mental health care (Boevink et al. 1996; Masthoff et al. 2005; Schalock and Verdugo Alonso 2002). All 8 domains of Schalock's framework were discussed during the focus groups. Most domains were mentioned by the respondents themselves, and if the participants didn't mention some of the 8 domains, the researcher added these missing domains to the discussion. There was also an opportunity to generate new categories or domains. An additional category concerning 'drug-related aspects' was created, but afterwards this extra category was merged into the domain of physical well-being.

5 Results

Below, the most important themes that resulted from the focus groups and their implications are discussed. The results are classified according to Schalock's (1996) eight domains of QoL. The domains 'personal relationships', 'social inclusion' and 'self-determination' are reported most extensively, as these items came up most frequently when talking about QoL with drug users. Table 2 indicates how the domains were operationalised for this study.

5.1 Personal Relationships

When asked about their perception of QoL, most drug users identified the importance of a supportive personal network, including family, children, friends, partner, and also care givers. Participants from the 'advocacy' and 'methadone treatment' groups didn't talk as much about a personal network, because most of them do not have family to lean on and have to look for support among professionals and/or other drug users. Most of the respondents said that how the social network functions is more important than who exactly is part of it.

First of all, it is important for the respondents to have somebody who supports them and to whom they can tell their story.

I want to continue with my outpatient treatment in that centre. I already go there for three years now, [...] and with my counsellor I always had one person that I could tell everything. She gave me some advice, and then at night—when I was lying in bed—I thought to myself: Maybe it's not such a bad idea, I will give it a try.

(Prison group (1); man, 22 years' old)

Other factors the respondents mentioned as evidence of support are: recognition, acceptance, understanding, affection and respect.

We all want the same: some happiness in our life. Living on the street is so hard, and there is nobody who will say to you: "If I was you, I wouldn't do that". Sometimes that is the only thing that you need, that you feel that somebody cares for you.

(Methadone treatment group; man, 48 years' old)

Apart from therapeutic opportunities a social network can provide, drug users who stayed in the psychiatric hospital and the therapeutic community also said they found it pleasant when they can enjoy 'the little things in life' with their network, for example, doing something nice together as a form of recreation. When talking about personal relationships, respondents

Table 2 Operationalisation of Schalock's (1996) QoL domains

| Domain | Indicators |
|------------------------|--|
| Personal relationships | Persons: family; friends; children; partner; professionals Functions: support; tell one's story; recognition; acceptance; understanding; affection; respect; redeem one's trust; recreation Key barriers: leaving the drug scene; isolation; loneliness; negative self-image; stigma |
| Social inclusion | Social participation Safe environment Structure Hobbies Work Key barriers: social pressure; limited possibilities; boredom; stigma; not having a clean record |
| Personal development | Discovering abilities Skills Education |
| Self-determination | Goals and challenges Making own choices Independence Structure External control |
| Rights | Concrete rights: housing; medical assistance; food Abstract rights: second chance; new start; privacy; freedom of speech; right to say no Deprived rights Duties |
| Emotional well-being | Inner rest Identity Find balance and set boundaries Time to change Coping Self-esteem |
| Material well-being | Housing Work Transport Financial security Paperwork |
| Physical well-being | Health care Sleep Balanced diet Sports Appearance and hygiene Self-care Drug-related problems: needle exchange; vaccinations individualised care; consumption rooms |

were asked how they looked at drug use in their circle of friends. Almost all respondents share the opinion that they would rather have friends who are not using drugs, but the reasons for this varied. Some respondents appreciate people who are still in the drug scene, but find it too difficult to hang around with them without using drugs themselves. Others think they can not trust other drug users, because they are only interested in their money or 'dope'.

If it comes to drug use, friendship doesn't exist. You never know if they are interested in you as a person or in your money. It's like the song of Doe Maar (Dutch band): friendship is an illusion.

(Methadone treatment group; man, 48 years' old)

A relationship is something most respondents postpone to the future, as they want to recover and work on themselves first. Many drug users have been dependent on someone for a long time and have never really lived on their own. Other respondents stated their relationship is a motivation to keep themselves 'on the rails'.

Maybe it is very selfish what I am about to say now, but now we just need some time for ourselves, come to our senses, that we can develop our personality again, before we throw ourselves into a new relationship.

(Detoxification group; man, 25 years' old)

Various respondents described some key barriers they face in trying to start a new life after their drug use. In the 'prison' group, the positive effects associated with drug use were reported as strong reinforcers, for example, the recognition you get and rituals such as 'scoring dope' and preparing a drug injection. In general, drug users find it very difficult to leave their social environment when they have been addicted for many years and consequently don't have any clean contacts. They lack the skills to do so, which sometimes results in extreme isolation and feelings of loneliness. Loneliness is an important barrier that was mentioned in all focus groups, and something almost all participants are struggling with.

There are a lot of moments in my life that I feel lonely. Sometimes I think if I wasn't a drug user, I wouldn't have ended up in this situation. I am isolated by my drug use and it made it hard for me to have enough people around me, who support me, who I can appeal to, who give me affection, ...

(Advocacy group; man, 39 years' old)

Another crucial factor appears to be individuals' self-image. Many drug users, especially in the 'advocacy' group, reported a negative self-image which affects their QoL. Some respondents stated that recovery is not worth the effort as they are convinced that they will never amount to anything in life, so why should they try? Respondents in the 'methadone treatment' and the 'advocacy' groups also reported feelings of shame: some participants are ashamed of their 'weakness' in not being able to cope with difficulties, or they are embarrassed to ask for help or to apply for a disability income; others were ashamed to tell the truth to their family, because they are scared they will reject them. From the 'therapeutic community' group it appeared that being confident and satisfied with yourself seems one of the factors positively influencing QoL.

The origins of these feelings are complex and influenced by different factors such as the social stigma that attaches to people with drug problems. Some respondents in the 'street corner work' and the 'prison' groups mentioned the negative influence of the prejudice and

discrimination they experience in society. A common opinion about drug users is that they are unreliable, manipulative, unmotivated and real ‘loafers’ (i.e. idle and unambitious). In the ‘detoxification’ group, it became clear that drug users sometimes use the way people look at them as an excuse to justify their behaviour, while others internalise the stigmatised identities other people give them. In the ‘prison’ groups, strong feelings of being unsuccessful were reported as respondents identified themselves with the stigma associated with drug use, in addition to the stigma of being a prisoner (cf. *supra*).

5.2 Social Inclusion

If people have a supportive social network it is sometimes a lot easier for them to re-integrate into mainstream society. Participation in the community appears to be important, but several barriers are mentioned that may hinder this. Sometimes people’s expectations are too high as integration involves much more than re-entering society as if one had never been marginalised from it. Respondents in the ‘prison’ groups particularly mentioned the difficulties they had living up to their own standards. In the ‘advocacy’ and the ‘prison’ groups, respondents reported that they carry a lot of traumas and injuries, which can inhibit their integration. In the ‘prison’ groups, they clearly expressed the need for support once they leave prison. They also stated that being physically integrated into society is not indicative of social inclusion as this can be hindered by isolation and stigma.

After 5 years in jail, when they let me out, I went to the shopping street in Ghent, and I will be honest, I peed in my pants because of the swarms of people. I can’t deal with masses anymore, pressure, I can’t talk normally to my parents. Sometimes, I close the door of my room, just like in my cell, so I don’t need to see anybody. People think you spend your time in jail, and then you come outside, and you are free again, and everything is normal, but you get a lot of injuries over there.

(Prison group (2); man, 34 years’ old)

Safety is a theme that was mentioned in almost all focus groups. Drug users strongly expressed the need for a safe living environment, with no drug users around, a place where they have some privacy, where they can feel at home and relax. Sometimes they have the feeling that their old neighbourhood stereotypes them, and that they will always be marked as drug users. Respondents stated they sometimes have a strong urge to start all over again, and many of them leave their hometown and move to another neighbourhood. In the focus group in the psychiatric hospital, participants agreed that safety is something they have to create for themselves, because danger and relapse are lurking everywhere. Almost all participants reported difficulties with daily activities. Most of them are facing boredom after stopping drug use, because when they were still using drugs this habit kept them busy 24 h a day. Consequently, in all focus groups respondents talked about the need for something to replace drug use, e.g., sports, a hobby, and other forms of recreation. This may also be a good opportunity to make new contacts.

I find it very important to keep myself busy [...]. Boredom is dangerous, it is dangerous to start using drugs again, because then I hang around on the street, I meet the wrong people, dangerous things.

(Methadone treatment group; man, 25 years’ old)

Something that is repeated by many participants in various focus groups is that structure can help to deal with boredom. Small things, like having breakfast or taking a shower can have a

positive influence in their life. This helps them to organise their day and not fall into that 'empty hole'. Another common theme linked with participation in the community is work. Most of the respondents comment that work is the best way to integrate in society, but several problems may arise. Many individuals expressed frustration because they only have limited possibilities and opportunities on the labour market. Most of them also lack qualifications, because they haven't finished school. In the 'advocacy' group, participants mentioned that a certain stigma is attached to the work that is often given to drug users. For example, most of the time they are offered a job in construction or as a street cleaner, but they seldom get the chance to do something they are really interested in. Most respondents also reported the importance of experiencing a certain appreciation for their work and receiving some respect for what they are doing. One person explained that sometimes they are regarded in a different way when they are working; all of a sudden they are no longer an (ex-)drug user, but a mechanic in a factory, with a responsibility. Further, the importance of work as a way of generating financial resources to increase QoL should not be underestimated.

For me, it is very important that I feel good in what I do, that by the end of the day I can be proud of what I have done. (...) It gives me satisfaction and also the money. You cannot deny that money is important to increase your own quality of life, so you can buy a small house, a car to go on vacation now and then. That's what I would work for, not to sit on my own and do nothing.

(Therapeutic community group; man, 24 years' old)

An important barrier that was mentioned by the 'street corner work' and 'prison' groups is imprisonment, since crimes committed to support their drug use often result in a criminal record, which may have a negative influence when looking for a job. A lot of jobs offered to drug users and other people with low qualifications and (long-term) unemployment are state subsidised employment contracts or jobs in the non-profit sector, where remuneration is low. This results in frustrations and feelings of not being respected, since most respondents want a 'normal' job and want to be paid for their work just like everybody else. On the other hand, several participants—particularly in the 'advocacy' and 'methadone treatment' groups, stated they can't deal with the social pressure of a fulltime job and prefer to do voluntary work, as this is more flexible. Other respondents mentioned the need for flexibility and individualised demands. For example, when someone follows methadone treatment, it is often very difficult to fulfil the expectations of an employer because they need to get their medication daily and are often sick, which affects their ability to work.

5.3 Self-Determination

Almost all participants in the focus groups mentioned the need for setting goals and challenges. They stated it is important for them to have prospects and to have a goal in mind. They talked about short-term goals to keep themselves busy, but also about future plans, so they have something to live for.

Prospects are very important for me, not to live from day to day, but to have a goal in mind. Not too much long-term, but like next month or next week, that I always have something on my mind, and also future plans, things I want to achieve, that I have something to live for.

(Half-way house group; man, 26 years' old)

Participants also said that they want to make their own choices, but some of them, especially in the ‘advocacy’ group, remarked that such choices are sometimes very limited in society. Respondents from the detoxification unit, the therapeutic community and the halfway house also reported a strong desire for independence, usually in relation to the product they were/are using. Most of them have been dependent on somebody for money, ‘dope’, a place to sleep, etc. for years, but now they want to be independent and take care of themselves.

Dependence I also find very important. That is something a lot of people, me included, have problems with. That is, I want to strive for, to be independent and to take my life in my own hands. In the past, I was always dependent on something or someone, and now it is very important to do things on my own.

(Halfway house group; woman, 33 years’ old)

Although dependence and making their own choices appear to be very important, participants also mentioned the need for some structure and certainty in their life, something to hold on to. The respondents from focus groups in residential settings particularly reported the need for advice and suggestions from other people. In several focus groups, there was discussion about the benefits and disadvantages of external control. Participants in the detoxification unit appreciate it if they have some control, and they explain that they need it to get a ‘kick’ from someone who tells them what to do concerning some aspects in their life. On the other hand, drug users who are not in treatment are very frustrated by the control imposed by their family or a judicial assistant. In most focus groups, participants talked about the importance of personal freedom, but they realised that it is sometimes very difficult for their family to give them this freedom, because of experiences in the past.

5.4 Personal Development

Particularly respondents from the focus groups in the halfway house, therapeutic community and psychiatric hospital reported the need to discover their abilities and to get the opportunity to learn things, since many of them had only been ‘surviving’ during their years of heavy drug use and had not really exploited the possibilities they have.

In the past, I was working in the construction industry. Now I am working with disabled people, and I like doing it. Those people are depending on you, they want to talk with you, and I can’t imagine I would have done this before, even not for one million euros. Now, when I look at myself, I notice I have more abilities, and I want to discover what else I have to offer.

(Half-way house group; man, 26 years’ old)

5.5 Rights

Issues concerning ‘rights’ were rarely mentioned spontaneously by the focus group participants, but when this topic was raised it was regarded as a necessity. The following quotation illustrates the way respondents address this domain:

The same rights as everyone else. Why would I be an exception, ... because I use(d) drugs? Why do they suddenly have to formulate different standards?

(Advocacy group; man, 42 years’ old)

When discussing the importance of rights, several people reported some specific rights, such as housing, medical assistance and food. Other rights were formulated at a more general level. A very significant right for them is the right to get a second chance and to have the possibility to make a new start. Many respondents have the feeling that they are deprived of some rights and that their rights are sometimes very limited. For example, when they need to fulfil certain conditions imposed by the criminal justice system, then they can't work or live where they want and cannot contact the persons they want.

5.6 Emotional Well-Being

Emotional well-being appeared to be an important domain for many drug users and in various focus groups the need to find some inner rest was frequently mentioned. Some respondents explained that having jobs, relationships and hobbies is no guarantee of being completely happy and stilling the 'restlessness' in their minds.

Several drug users stated that after years of using drugs, some people need to build up their identity again. During the period that they were using drugs, their personality was 'frozen' and now—many years later—they feel 'different' as compared to other people of their age.

It is difficult to get into contact with new people. They have built up their own life, they have friends, hobbies, a family, or whatever, and we still need to build up all those things. If you meet somebody, automatically they talk about those things and we can't take part in that conversation. At a certain moment, time stood still, also with regard to interests. We can't talk about the things they are interested in, because you have been in a world of drug use, and all the rest has not been developed further.

(Psychiatric treatment group; woman, 27 years' old)

Coping is one of the skills that is strongly linked with emotional well-being and that was discussed in all focus groups, such as the ability to deal with feelings of fear, depression, set backs and social pressure.

We tasted the forbidden fruit and if things go wrong, you fall back on what pleases you most. For me, this is heroin.

(Methadone treatment group; man, 48 years' old)

5.7 Material Well-Being

Another theme that drug users frequently discussed concerning QoL are material expectations. This issue was identified as a high priority in the 'methadone treatment' and 'street corner work' groups. They stressed the importance of having at least the basic comforts such as housing (electricity, warm water, ...), affordable accommodation, transport, food and an income. Furthermore, the continuity of this material security is regarded as crucial, particularly among drug users in the 'advocacy' and 'halfway house' focus groups. As one person explained:

If everything is just affordable and I am not in trouble the whole time, I don't have to be stressed and worried the whole night. If you have transport, a place to sleep, a job, and a lunchbox with something extra, then it is fine for me. But the most important is that it lasts, and that there are no extreme peaks.

(Halfway house group; man, 26 years' old)

5.8 Physical Well-Being

Surprisingly, drug users rarely associated physical health spontaneously with quality of life, but when this theme was raised by the researcher they considered it of vital importance. Access to health care (e.g. general practitioner, gynaecological check-up, dental care) appears to be of primary importance to them. Also interventions and measures to deal with drug-related health problems, such as vaccination and needle exchange programs, are evaluated as crucial (e.g. abscesses, gastro-enteric problems, lung diseases, reduced resistance).

According to most respondents care givers in drug treatment centres mainly focus on drug use and far less on other, for the client (more) important domains. Drug users' expectations about drug treatment vary, but several participants from the 'advocacy' and 'methadone treatment' groups stressed the importance of getting immediate help (rather than end up on a waiting list for a couple of weeks) and of treatment that deals with the multiple causes and consequences of their drug use, and not solely with their drug use. They find it important that there is a focus on other relevant life domains (e.g., family, housing) that they have difficulties with in substance abuse treatment.

When you make the first step to ask for help and you go to a drug treatment service, if I ask for help today, and I need to wait for six weeks, six weeks later I won't even think about it anymore. I will have my mind on other things (...). Immediately you think that they don't want to help you, and that gives you an excuse to start using drugs again.

(Methadone treatment group; woman, 37 years' old)

6 Discussion and Conclusions

Our exploration of drug users' subjective perceptions of QoL using nine focus groups with drug users from various backgrounds and in different stages of recovery suggests that QoL is not primarily associated with health and involves much more than the aspects typically represented in measures of HRQOL (Michalos 2004). The results of this study fit with findings from the field of disability studies and mental health care (Boevink et al. 1995; Cummins 2005; Schalock and Verdugo Alonso 2002). In the following section, we explore this connection further.

6.1 More than Health-Related Quality of Life

The most common themes that drug users related to a good QoL were personal relationships and social inclusion. Also people with psychological problems mention the positive influence of social support on their QoL (Schalock and Verdugo Alonso 2002). However, both groups frequently lack this kind of support. Isolation and social stigma may contribute to the fact that social inclusion is often difficult to achieve. Padaiga et al. (2007) have demonstrated that stigmatization may have an influence on understandings of QoL. In the field of mental health care, stigma appears to have negative consequences for the QoL of clients and frequently results in discrimination (Rosenfield 1997). Some respondents from our focus groups reported that after a while, they started to behave according to the stereotypes and a comparable form of 'learned helplessness' has been found among people with disabilities (De Waele and Van Hove 2005). Some participants in the focus groups

reported difficulty re-integrating into society, because they have the feeling that there is a huge gap between them and the other people in society.

Drug users and people with disabilities mention a lot of injuries and traumas in their life that influence their current QoL. Regarding their integration in society, they reported the need for a safe neighbourhood to live in. People with disabilities also stressed the desire to live in a normal street with 'normal' people and not be placed in specialised institutions (Van Loon 2001). This resonates with the desire of drug users to live in a safe environment with no other drug users around, where they are seen as human beings and not only identified as 'drug users'. Also, in mental health care, there has been much interest in deinstitutionalization and integration of patients in the community, as studies show that this is usually the preference of people with mental health problems (van Nieuwenhuizen et al. 2002). However, we should be careful that we don't confuse social inclusion with physical integration, because being 'part' is more than just being 'there'.

Regarding self-determination, many respondents stressed the importance of making their own choices and being independent. Comparable results were found in the literature on persons with chronic mental illness (Boevink et al. 1995). Another clear link we found between drug users and people with disabilities is the role of control in their life. Both groups frequently criticize the level of control by others, e.g. family, the criminal justice system and care givers (De Waele and Van Hove 2005). Having hopes and prospects for the future is also something that is deemed very important across the three groups (Boevink et al. 1995). These themes therefore cannot be neglected when measuring QoL. Schalock (1996) views inclusion and self-determination as two of the most important dimensions of QoL, which was illustrated by the fact that both domains were discussed extensively in our focus groups.

On inquiry, it became clear that in addition to personal relationships and social inclusion domains such as personal development and rights were considered very important. Such dimensions are usually not included in health-related approaches to QoL and require a much broader conceptualisation of QoL. Rights is also the domain that got the lowest attention in QoL-research on mental health care (Schalock and Verdugo Alonso 2002). According to the respondents issues concerning self-determination and rights are seldom addressed in drug abuse treatment. There is a clear need for employing more widely and systematically important support and treatment principles like participation, self-determination, and empowerment, and taking a strengths approach in this field (Saleebey 2006). Moreover, a comprehensive and continuous approach is required in substance abuse treatment in order to deal adequately with drug users' multiple and often long-term problems, and not reducing these problems to drug use. Case management, in particular the strengths-based model of case management, is such an intervention that acknowledges the unity and multiplicity of clients' problems and helps them to link with needed services (Rapp 2006; Vanderplasschen et al. 2004).

Drug users also stressed the importance of material and emotional well-being, especially the role of coping mechanisms and a positive self-image. Surprisingly, limited attention was given to physical health by the various focus groups; in fact, physical health was something that was rarely introduced spontaneously. This doesn't mean that their physical health is not important for them, just that it is not the first thing they associate with QoL. This raises the question of whether the sole focus on health-related QoL in drug use research honours the true meaning of this concept as perceived by drug users. We can at least conclude that there is a strong discrepancy between the perception of drug users themselves and the dominant conceptualisation of QoL (Fischer et al. 2001a, b).

The three domains of well-being are also strongly linked with the provision of ancillary services: physical health care, housing services, supported employment, etc. By focusing

on providing ‘care’ or ‘services’ ‘quality of life’ might be reduced to ‘quality of care’. This has the potential to diminish drug treatment agencies, as taking care of people is the duty of society and can be clearly delineated, based on quality indicators such as effectiveness, efficiency, and continuity (De Waele and Van Hove 2005). Our research findings indicate that QoL should become a leitmotiv not only in substance abuse research, but also in substance abuse treatment and that it should be incorporated and hold a central position in the discussion about providing quality of care.

6.2 Between-Group Differences

In general, there was agreement that the 8 domains discussed in the various focus groups are important for a good QoL, but the interpretation of these domains varied between individuals and focus groups. Most of the group differences occurred between persons in and out of treatment (or in low threshold treatment). Drug users involved in low threshold treatment are often in a socially more disadvantaged situation. They report more frequently the lack of a social network, a negative self-image, problems due to stigma and discrimination, and difficulties dealing with social pressure and control. They also stress the importance of material well-being. Respondents who followed residential treatment focused less on these aspects since they are part of their treatment program and more support is provided in dealing with those aspects.

Our findings illustrate that drug users perceive QoL as a broad concept, including various life domains. However, in the field of drug abuse research the focus on QoL, if any, has usually been limited to health-related aspects of QoL. Standards of treatment are usually developed without input from the treatment population, so there is no certainty that these treatment goals correspond with clients’ perception of QoL. Consequently, it will be important to strive for an ‘emic’ understanding of QoL (Rapley 2003), which is based on individual experiences, rather than a standard definition of QoL. These results strongly confirm the multidimensionality of QoL, which suggests the need for a comprehensive model that emphasizes the holism of this concept (Schalock and Verdugo Alonso 2002). When we shift the focus from more conventional outcomes (e.g. no drug use, no criminal activities, work, etc.) QoL appears as a broad concept influenced by much more than physical and mental health. It is not always problems with drug use that make substance abusers go into treatment, but rather problems in other areas of their life such as social and psychological problems (Ryan and White 1996). These domains should therefore get more attention in drug abuse treatment. Although they are not directly linked to individuals’ health status, they may influence clients’ motivation to maintain the efforts they have initiated (e.g. to become clean) or increase the risk of relapse and therefore have an indirect influence on their HRQOL. As many diverse factors influence QoL, there is a need for a comprehensive assessment of QoL and a comprehensive approach to service provision (Vanagas et al. 2006). Treatment should be based on clients’ needs (rather than what is supplied or on offer), as there is a strong link between clients’ self-rated needs and their subjective QoL (Lasalvia et al. 2005). If the needs mentioned by clients themselves are appropriately addressed, an improvement in their subjective QoL can be expected. Active participation of clients in their own treatment process, based on principles of empowerment and inclusion will have a positive influence on their QoL (Schalock and Verdugo Alonso 2002).

In summary, this study presents perceptions and attitudes of drug users concerning the concept of quality of life and may provide a framework for paying more attention to these perspectives in research that is intended to influence their lives. Moreover, involving people in research about their own lives is potentially emancipatory (Rapley 2003).

Treatment can be made more effective by basing it on drug users' personal needs. Additionally respecting and understanding the views of people with drug problems will be necessary if we want to gain insight into the factors and experiences that really influence their QoL.

6.3 Limitations of the Study

Some methodological limitations of this study should be taken into account. First, focus group results cannot be generalized as they reflect the individual experiences of clients from within their own frames of reference. One of their benefits is that they bring about social interaction among the participants and provide insight into the perceptions of a group of people that would not come up in individual interviews (Krueger and Casey 2000). Another advantage is that people who cannot read or write, or people who are not comfortable in individual interviews can participate in focus groups (Kitzinger 1995). Face-to-face interviews would be more likely to provide information specific to individuals and address the complexity of their life experiences. Secondly, the sample size of our study and the number of focus groups was relatively small. Nevertheless, saturation of information was found at the end of the focus groups and the study was not aiming to generate quantifiable data. Accordingly, further research will be useful to substantiate our findings. Thirdly, our analyses can be influenced by personal opinions while coding and structuring the data. We tried to minimize this potential bias by working with various coders to increase the reliability.

For future research, it would be useful to make a shift from participative to emancipatory research (Gilbert 2004). In participative research, researchers and participants collaborate, but the bulk of responsibility and decision-making rests with the researcher (Walmsley 2001). In emancipatory research, participants themselves develop the structure and interpretation of the research; the expertise of the researcher assumes secondary status in relation to the input of participants themselves. By fostering an emancipatory approach, drug users can become key-decision makers in the treatment process, which will contribute to their QoL and, most likely, to positive treatment outcomes.

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