Quality of life among opiate-dependent individuals after starting methadone maintenance treatment

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TAHITIAN MOON

My boat's capsyzed it's gonna sink to the bottom

I can see the lights on the shore getting farther away

I dont if I'll make home tonight

But I know I can swim under the Tahitian moon

I came out here tonight to look for my friend

I dont know if I'll ever get to see him again

I dont know if I'll make home tonight

But I know I can swim under the Tahitian moon

One last time under the Tahitian moon

The sea is a very easy place to disappear

To drift away, to fall in love or make your peace

I came out here tonight to look for my friend

I dont know if I'll ever get to see him again

I dont know if I'll make home tonight

But I know I can swim under the Tahitian moon

(Perry Farrell, 1996)

Preface

"Heroin addicts are lazy skumbags!"

"Methadone users are profiteers and live from the taxes we pay"

"Heroin users should be put in jail"

"Once a junk, always a junk"

"Never trust a drug addict"

"Addicts don't want to change!"

"Heroin users are marginalised, dangerous criminals"

"Methadone is trading one addiction for another"

"People who use methadone are bad parents"

"Methadone causes patients to become alcoholics"

"Methadone is more addicting than heroin"

"Heroin users are only interested in dope and money"

"People get on methadone just for the high"

These are only a few examples of prejudices and myths about methadone and opiate users - often fed by the mass media - that arise when you tell people you are writing a dissertation on heroin users following methadone treatment. Although there might be an element of truth in some of these prejudices, these citations represent a very unilateral view about opiate-dependent individuals, whose lives do not necessarily match with the stereotype picture of a lazy, filthy junk…

Extensive research has already focused on interventions to reduce the harms drug use causes to society and to restrict the related nuisance to a minimum. Without denying the usefulness of these interventions, this dissertation wants to demonstrate that there is also another side of the picture, seldom raised in the media and unknown by the majority of people in the general population…

In contrast with the dominant focus on socially desirable outcomes in substance abuse research (e.g. no more drug use, no illegal activities), this dissertation starts from a different viewpoint, with a focus on outcomes important for opiate users themselves. Specific attention is given to opiate-dependent individuals' *own* perspectives and ideas about *their life*. This dissertation should be seen as an effort to start from subjective perspectives, in our rather alienating, modernist society, by listening to opiate-dependent individuals' own voices. In what follows, you will find outlines of my efforts to enter into the world of people who are labelled as opiate-dependent…

The central aim of this dissertation is to explore the concept 'Quality of Life' (QoL) in opiate-dependent individuals and how QoL can be successfully integrated in the treatment and support for opiate-dependent individuals. Attention is given to how opiate-dependent individuals define the concept of QoL, factors that influence their current QoL and the impact of following methadone maintenance treatment on QoL.

In *chapter 1*, the broader context of this dissertation is outlined and the aims and research questions are discussed. *Chapter 2* explores the conceptualisation of the concept QoL by drug users. C*hapter 3* addresses findings, shortcomings and limitations of current QoL research among opiate-dependent individuals, based on a systematic review study of the literature. *Chapter 4* and *5* describe opiate-dependent individuals' current QoL, with attention for possible determinants of QoL and a specific focus on the indirect effects of current heroin use. *Chapter 6* provides an in-depth exploration of the impact of methadone maintenance treatment on opiate-dependent individuals' QoL. A general discussion (*Chapter 7*) completes this dissertation and assesses the scientific, clinical and social relevance of this study, including a focus on its limitations and recommendations for future research.

This dissertation comprises several papers, which have been submitted for publication, are currently under editorial review or have already been published. Consequently, to make each of the papers self-containing and to meet the editors' requirements, the content of some of the chapters may overlap.

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me. Providing me with a nice meal, joining me for a walk with the dog, listening to my stories and understanding the fact that I sometimes just didn't feel like talking, are only some of the small things that were of great value for me during the last months. I hope I can make you proud today.

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Chapter 1

General Introduction

Abstract

In this chapter, we introduce the major themes of this dissertation: opiate dependence, methadone substitution treatment and quality of life (QoL). We look at the nature and extent of opiate dependence and related health and social consequences. Attention is given to the establishment of harm reduction initiatives, in particular methadone substitution treatment, which has become the standard treatment for opiate dependence. The chronic nature of opiate dependence and the need to enlarge the focus of treatment outcomes to concepts relevant for opiate users themselves, such as QoL, is demonstrated. The historical background of QoL and a number of conceptual and methodological issues related to this concept are discussed. Subsequently, the orthopedagogical perspective of this dissertation is illustrated. Finally, the aims of this study are described as well as the study sample, setting and research methodology.

"It did not feel like something that was going to take over my life and destroy it. It felt like a subtle flower instead of a manipulative demon. That's the mystery of heroin."
Corey Feldman (1971 -)

1.1 Opiate dependence

1.1.1 History, prevalence and consequences

The history of opium use dates from ancient times. Opium was already used by the Egyptians and many other nations from the Middle East. Also, in the Greek mythology opium was consumed by some persons (Van Epen, 1995). The goddess Demeter discovered that her grief diminished when she took opium. Homer (Ninth century, B.C.) described it as follows: "She cast a drug into the wine of which they drank to lull all pain and anger and bring forgetfulness of every sorrow" (Brownstein, 1993). Opium, often consumed in the arts scene since the beginning of the nineteenth century, was initially used for its calming and euphoric effects, and related problems were only reported much later (Miller & Tran, 2000). Nevertheless, in the seventeenth century smoking of opium already resulted in a major boom of addiction problems in China (Brownstein, 1993). Heroin, a synthetic derivate, which name is derived from the heroic feeling it brings about, came much later (1874). The Bayer laboratories started the production of heroin in 1898, as a non-addictive substitute for morphine. Soon, heroin was noted to be as addictive as morphine, and resulted in a number of serious social consequences (e.g. crime) (Miller & Tran, 2000). In 1913, Bayer decided to stop making heroin, given the addictive properties of the drug. Since that day, the illicit production and trafficking of heroin has been growing.

In Europe, it is only since the seventies that the use of opiates, mainly heroin, has been associated with problematic drug use and related problems (EMCDDA, 2009). In the last decade, opiate dependence continues to be a serious health and social problem, urging for innovative and effective interventions to deal with it. In 2009, the World Health Organisation estimated that about 15.6 million persons of the world population are illicit opiate users. The majority of them (11 million) uses heroin (WHO, 2009). The worldwide prevalence of opiate use ranges from 0.3 to 0.5% of the total population (UNODC, 2010). Nevertheless, the life time prevalence of opiate use shows extreme variations between various countries (e.g. the United States, the Netherlands) (Vega et al., 2002). In the European Union, the prevalence of problematic opiate use ranges from 1 to 6 per thousand inhabitants (between 15 and 64 years old). Heroin that is used in the

European Union is mainly coming from Afghanistan, one of the world's leading partners in heroin production (EMCDDA, 2009). Belgium can be situated in the middle group as compared with other European countries. Until 2008, no official figures were available on the use of opiates in the general population in Belgium (De Donder, 2009). In 2008, the Scientific Institute for Public Health in Belgium organized a household survey, investigating, among other things, the prevalence of illegal drug use in the general population. In total, 14,549 households, spread over the three districts (Brussels, Flemish and Walloon district) were contacted to participate in the survey (39.9% actually participated). This health survey demonstrated low prevalence rates (last year) (0.2%) for the use of opiates in the general population. This percentage was highest among persons between 15 and 34 years old (0.4%) (Van der Heyden et al., 2009).
The use of opiates does not necessarily result in a dependency problem; a study concerning the epidemiology of dependence on legal and illegal substances in the general population in the United States, revealed that approximately 25% of the people who used opiates at least once in their life developed an opiate-dependence (Anthony, Warner & Kessler, 1994).

Although opiates are only used by a minority of the world population, the cost of opiate-abusing individuals to society is high (e.g. due to unemployment, illegal activities) (WHO, 2004; Clark, Gospodarevskaya, Harris & Ritter, 2003; Xie, Rehm, Single, Robson & Paul, 1998; Choi, Robson & Single, 1997) and dependence rates are much higher among opiate users as compared with other drug users (EMCDDA, 2008). Moreover, the majority of opiate-dependent individuals can be described as poly-drug users, frequently using other substances (e.g. cannabis, cocaine, crack) (Fischer et al., 2005; Leri, Bruneau & Stewart, 2003). In addition, the vast majority of drug-related deaths and morbidity (e.g. infectious diseases) is associated with opiate use, mostly heroin (Bargagli et al., 2005; Darke & Hall, 2003). Mortality rates of opiate-dependent individuals are high, especially among those injecting their drugs (between 6 and 20 times higher than among the general population) (WHO, 2004). Frequently mentioned health consequences in this population are: infection with HIV, transmission of hepatitis C virus, lung abscesses, … The majority of these health complications are found among injecting opiate users (Hedrich, Pirona & Wiessing, 2008; EMCDDA, 2008; Fischer, Haydon, Rehm, Kraiden & Reimer, 2004; Bruneau et al., 1997). Opiate users who are seeking treatment are more often unemployed, have lower levels of education and more psychiatric problems as compared with non-opiate users (EMCDDA, 2009). In general, opiate dependence is associated with serious problems in different life areas (e.g. economic, psychological, health) (Vanderplasschen, Rapp, Wolf & Broekaert, 2004). Consequently, it may not surprise that opiates remain the primary drug for

which individuals seek treatment and the number of individuals seeking treatment for primary heroin use still increases (Lamkaddem & Roelands, 2010; EMCDDA, 2009).

1.1.2 Harm reduction and methadone substitution treatment

The above-mentioned findings illustrate the need for a variety of approaches in substance abuse treatment, including harm reduction (EMCDDA, 2000). Originally, substance abuse treatment was characterized by a drug-free approach, in which drug-free therapeutic communities had a prominent place. Nevertheless, due to high relapse rates and the recognition that one single treatment modality does not meet the needs of all individuals with substance abuse problems, the need for an integrated treatment approach, including harm reduction initiatives, has been put forward (Broekaert & Vanderplasschen, 2003). In the fifth action plan on drugs of the European Union (2009-2012) extensive attention is given, among other aspects, to the reduction of harm caused by the use of drugs. Harm reduction is characterized by a humanistic, non-judgmental treatment approach, with respect for the autonomy of individuals using drugs. It emphasizes their rights for health care (Brocato & Wagner, 2003; Denning, 2001). The primary goal of harm reduction is not to combat the use of drugs, but to diminish the harm associated with drug use (Windelinckx, 2003; Lenton & Single, 1998). Such a pragmatic approach, starting from a comprehensive and integrative drug policy including prevention, abstinence-oriented treatment and harm reduction initiatives, has become generally accepted in the last decade (Rhodes & Hedrich, 2010; Broekaert & Vanderplasschen, 2003; Marlatt, Blume & Parks, 2001).

Substitution treatment, mainly extramural, is one of the pillars of the harm reduction approach (EMCDDA, 2009; Gerlach, 2002; Rosenbaum, Washburn, Knight & Irwin, 1996). The main goals of substitution treatment are the reduction of illicit opiate use, preventing harm caused by the use of opiates and improving opiate-dependent individuals' well-being (WHO, 2009; Amato et al., 2005). Substitution treatment is one of the most effective forms of treatment for opiate-dependent individuals, for whom an abstinence-oriented approach is not always adequate from a short-term perspective (Mattick, Breen, Kimber & Davoli, 2009; WHO, 2004). This is further stimulated by the chronic and relapsing character of opiate dependence, urging for a long-term treatment approach (Van den Brink & Haasen, 2006). In 2007, an estimated number of 650.000 opiate users in the European Union had followed a type of substitution treatment (EMCDDA, 2009); which is more than twice as much as in the year 2000 (EMCDDA, 2000). Estimations of the number of opiate-dependent individuals following treatment in the European Union show that 40% of all

problematic opiate users are involved in some form of substitution treatment, mostly methadone (70%). Nevertheless, enormous variations between countries are noticeable (EMCDDA, 2009).

Since Dole and Nyswander (1965) demonstrated the effectiveness of methadone as a substitute drug for heroin, methadone has slowly become an important mainstay in substitution treatment and a key element of the establishment of harm reduction initiatives in the last decade. Methadone is a long-acting opiate agonist that causes physiological stability, eliminates opiate withdrawal symptoms and blocks the euphoric effects of heroin use (Mattick et al., 2009). In general, methadone substitution treatment is the standard, evidence-based treatment for opiate dependence in most countries and many studies have evaluated its effectiveness, demonstrating a reduction of heroin use, risk behaviour (related to injecting drugs) and drug-related crime, and prolonged treatment retention (Mattick et al., 2009; Amato et al., 2005; Ward, Hall & Mattick, 1999; Farrell et al., 1994). There is abundant evidence that methadone maintenance therapy and higher doses of methadone (> 60mg) are both more effective than detoxification with methadone and lower doses of methadone in achieving abstinence and prolonging treatment retention (Bao et al., 2009; Mattick et al., 2009; WHO, 2009; Amato et al., 2005; Sees et al., 2000). Furthermore, (voluntary) psychosocial therapy in addition to the medical supply of methadone, appears to be an essential component of substitution treatment (Amato et al., 2004; WHO, 2004; De Ruyver, Bosman, Bullens & Vander Laenen, 2001; McLellan, Arndt, Metzger, Woody & O'Brien, 1993).
Although the effectiveness of methadone treatment has been repeatedly shown, no single treatment form is effective for all people, and attention for alternative treatment forms is necessary (e.g. when clients fail to respond or experience adverse effects) (WHO, 2009; Haasen & van den Brink, 2006). A number of studies have already demonstrated the usefulness of buprenorphine as a long-term alternative for maintenance treatment of opiate-dependent individuals (Mattick, Kimber, Breen & Davoli, 2008; Maremmani, Pani, Pacini & Perugi, 2007; Giacomuzzi, Ertl, Kemmler, Riemer & Vigl, 2005). Recently, the prescription of diamorphine (heroin) has been introduced for clients who failed previous episodes in methadone treatment (Ferri, Davoli & Perucci, 2003). In Europe (e.g. Germany, Switzerland, the Netherlands), heroin-assisted treatment has shown positive effects among opiate-dependent individuals who did not benefit from other forms of treatment in the past (Haasen et al., 2007; van den Brink, Goppel & van Ree, 2003; Rehm et al., 2001). Nonetheless, further research is necessary to investigate the usefulness of legal prescription of diamorphine in the treatment of chronic, treatment refractory opiate-dependent individuals (regardless of previous maintenance treatment) (Haasen, Verthein,

Eiroa-Orosa, Schäfer & Reimer, 2010). In the near future, a controlled heroin trial will be set up in the city of Liège (Belgium) to investigate the possibilities of this treatment form for heroin users who did not benefit from other forms of treatment. The existence and availability of alternative treatment forms creates the possibility to match clients with the best treatment available for his/her personal situation at that moment.

1.1.3 Substitution treatment in Belgium

The legalisation of methadone treatment in Belgium took a long time and was rather complicated (Pelc et al., 2005). In 1975, there was a first peak of heroin use in Belgium, mainly in Brussels, but at that time prescription of methadone was still exceptional (Y. Ledoux, pers. comm., 10th June, 2008). In the eighties, there was an upcoming interest in the use of methadone as a substitute drug for opiate dependence in the medical field, but the Law on Narcotic Drugs of 24 February 1921, prohibited the provision of methadone, because it was regarded as maintaining an addiction (Pelc et al., 2005). In 1994, a consensus conference on substitution treatment ended in a number of guidelines (e.g. concerning the recommended doses) for the prescription of substitute drugs. As a result of this consensus conference, the Law of 1921 was no longer enforced and the decision to prescribe methadone as a substitute for opiate dependence was consigned to the medical authorities. This juridical tolerance resulted in a rise of the number of individuals who benefited from the positive effects of methadone substitution in Belgium, with an improvement of the public health as an additional result (Pelc et al., 2005). In 1995, the Belgian federal government formulated an action plan for illegal drugs, starting from a harm reduction approach, to deal with this complex phenomenon and the often associated social nuisance (De Ruyver et al., 2001). One of the 10 concrete actions of this plan, was the establishment of socio-sanitary centres for drug users. This form of low threshold treatment was supposed to focus on marginalized groups of drug users and substitution treatment was one of the basic pillars of the services provided. This need for low-threshold services for drug users was further emphasized by the work of a Belgian Parliamentary Working Group in 1997, which started from a global and integrated treatment approach (De Ruyver et al., 2001; De Ruyver, Casselman, Meuwissen, Bullens & Van Impe, 2000). The findings of this Parliamentary Working Group resulted in the formulation of the federal drug policy note of January 19th, 2001. Harm reduction, including substitution treatment, was one of the central pillars in this federal drug policy note. The focus in this policy note was on care directed to reintegration and a reduction of the health risks involved with the use of drugs (Federal Drug Policy Note, 2001). Furthermore, the

necessity of a multidisciplinary approach was stressed, with attention for the social, medical and psychological problems associated with drug use.
Nevertheless, the establishment of harm reduction initiatives in Belgium came relatively late and it took a long time before this approach became fully integrated in substance abuse treatment (De Ruyver et al., 2001). Consequently, it was only in August 2002 that the prescription of substitute drugs for opiate dependent persons was legalized and that the juridical gap was removed (Law 22 August 2002) (Pelc et al., 2005). This law was further adapted by the Royal Decree of 19 March 2004, in which the conditions for a physician to provide substitute drugs were further specified (e.g. registration of substitute drugs). Due to the Royal Decree (2004), general practitioners and specialists have to follow training in order to be qualified for starting up substitution treatment. On October 6th, 2006, another royal decree modified the Decree of 19 March 2004 on substitution treatment. This new decree obliges general practitioners who prescribe substitution treatment to two or more patients to register in a day centre, a network for drug users or a specialized centre for drug treatment (Lamkaddem, 2009).

The legalisation and development of substitution treatment in Belgium has known an enormous increase between the end of the eighties and today. Consequently, enormous regional differences can be identified in the organisation, prescription and distribution of methadone (Lamkaddem & Roelands, 2010; Pelc et al., 2005). In the Flemish community, methadone substitution treatment is mostly supplied by specific, low-threshold services for drug users while only a small percentage of methadone is prescribed by general practitioners. This is in contrast with the French community, where the majority of methadone prescriptions are offered by general practitioners (Lamkaddem & Roelands, 2010). Apart from general practitioners, substitution treatment in Belgium is currently provided in 27 outpatient services for drug users, 70 hospitals and 15 prisons (Schulte et al., 2008). In general, the prevalence of the prescription of substitute drugs is much higher (3.81 times) in the French community, compared with the Flemish community. Based on the number of persons insured in Belgium between August 2006 and July 2007, it is estimated that approximately 3596 individuals follow methadone substitution treatment in Flanders on a yearly basis. According to the latest available estimates, a total of 14,480 clients follow methadone treatment in Belgium (Ledoux, 2008).

1.1.4 The local situation in Ghent (East-Flanders)

Ghent (the setting of this dissertation), the capital of East-Flanders is a medium-sized city, with around 243,000 inhabitants (2010). Since the start of the drug epidemic in Flanders, several initiatives for drug abusers have been set up around the city of Ghent. Due to the centralised position of the city and the high concentration of services for drug users, Ghent is a magnet for treatment-seeking drug users from all over Flanders (De Ruyver et al., 2001). Historically, the region around Ghent was one of the first in Belgium offering treatment services for individuals with substance abuse problems. Different types of treatment services, such as psychiatric hospitals, therapeutic communities and outpatient centres can be consulted in the region. Given the lack of coordination and continuity of care between these services (Vanderplasschen, De Bourdeaudhuij & Van Oost, 2002), serious efforts have been undertaken in this region to coordinate service provision for clients consulting various services and for establishing an integrated network of treatment services (Vanderplasschen et al., 2004). Furthermore, since December 2001 tri-weekly client conferences ("Cliëntoverleg Drugs" (COD)) are organised with all agencies offering services to substance abusers in the region of Ghent. One of the aims of these client conferences is to improve the collaboration and referral between services in response to the growing number of treatment demands of substance abusers in the region of Ghent (Franssen, 2003). Recently, initiatives have been taken to refer clients who committed drug-related crimes to treatment (e.g. drug treatment courts), resulting in even higher treatment demands in these agencies.

Looking at substitution treatment in particular, Ghent had an important role in the evolution and growth of methadone substitution treatment in Flanders. One of the first low threshold socio-sanitary centres for drug users opened September 1st, 1995, in the city of Ghent. In 1997, the medical component of this centre was further elaborated and resulted in the first medical-social care centre (MSOC). The majority of the individuals following treatment in the medical-social care centre receive methadone substitution treatment for their opiate dependence. The centre aims at a multidisciplinary approach with attention for the medical, social and psychological components of opiate dependence. The objective of the medical-social care centres, as formulated in the annual report of 2008, is to improve the QoL of drug-dependent individuals and their direct environment (Annual report MSOC Gent, 2008). Clients who contact the medical-social care centre find themselves often in socially marginalised situations and frequently experience psychiatric problems. About three-quarter of them have the Belgian nationality (76.7%), and a limited number of clients are, among others, of Turkish, Moroccan or East-European origin. Besides their opiate dependence, a

large group also reports cocaine dependence (20%) or abuse (40%), and the majority of them are poly-drug users.

Recently, a growth of clients following methadone substitution treatment in East-Flanders is noticeable (from 536 in 2005 to 842 in 2007), with a remarkable number of clients younger than 25 years (34.8%) (Ledoux, 2008). Two hundred and eight physicians prescribe methadone in East-Flanders and 1369 clients receive methadone treatment on a yearly basis (prevalence 9.79/10,000 inhabitants). Between August 2006 and July 2007, 545 insured patients received methadone substitution treatment in the region of Ghent (prevalence 10.63/10,000 inhabitants). The majority of these clients get their methadone prescribed and distributed in the medical-social care centre of Ghent. At the end of 1998, the centre provided care to 615 opiate-dependent individuals. Ten years later, 748 unique clients were followed in the same centre (Annual report MSOC Gent, 2008). Besides the prescription of methadone in the medical-social care centre, methadone is also prescribed by a number of general practitioners and by doctors in the day-care centre of De Sleutel in Ghent.

Given the high number of individuals following methadone treatment in Ghent and the existence of a strong regional network of drug treatment services to support and follow-up these clients, the region of Ghent was chosen as the setting for this dissertation. As a result of the high concentration of services for drug users in Ghent, several drug abusers come to Ghent for treatment. Consequently, the participants in our study are not necessarily residents from this region.

"The quality, not the longevity, of one's life is what is important."
Martin Luther King, Jr. (1929 - 1968)

1.2 Quality of life (QoL)

1.2.1 The rise of the concept QoL

Attention for the essential aspects of a good life is an age-old theme, discussed by various philosophers (e.g. Aristotle), but the specific use of the term 'quality of life' only occurred more than 2000 years later. During the 20th century, QoL has become an important standard in different domains (e.g. economic, medical, social) of our modern society.

The term 'quality of life' has first been used after World War II, to describe the effect of material welfare on individuals' lives. Due to the *economic* prosperity and the improved standard of living at the end of the war, an upcoming interest for the concept QoL was noticed in the *general population* (both at societal and individual level). This economic model of QoL was related to material goods (e.g. car), without attention to the subjective well-being of individuals (Cummins, Lau & Stokes, 2004).

In the 1960's, this exclusive focus on the wealth of individuals was questioned and the conceptualisation of QoL was extended to issues such as family, health and housing in order to gain insight in the QoL of society as a whole, the so-called 'social indicators' movement (a social, scientific index of the well-being of the general population) (Rapley, 2003; Farquhar, 1995).

From the 1970's, increasing attention has been given to QoL in health care research and clinical practice (e.g. oncology, psychiatry), especially for patients with chronic disorders (Moons, Budts & De Geest, 2006). The tremendous developments in the medical field and health care system resulted in an increased life expectancy, but also in a higher number of individuals facing chronic illnesses (Moons et al., 2006). Attention was no longer only given to how the life of individuals suffering from illnesses could be prolonged (quantity), but also to how their sense of well-being could be improved, including a focus on non-disease aspects (quality) (Katschnig, 2006; Farquhar, 1995). In 1977, QoL appeared for the first time as specific keyword in the Index Medicus.

However, QoL is often simplified in the *medical field* to a description of a person's health status, often referred to as health-related QoL (HRQoL). The concept of HRQoL is frequently misused as a synonym for QoL (Cummins et al., 2004). HRQoL focuses on the effects of a disease or health conditions on the daily functioning of individuals (Wiklund, 2004), with special attention for their physical and mental health (Mooney, 2006; Millson et al., 2004). The focus in

HRQoL is on pathology and deficits, while QoL has a more positive connotation, including attention for persons' overall well-being and satisfaction with life (Laudet, Becker & White, 2009). HRQoL is characterized by a '*judgmental approach'*; individuals are supposed to judge their situation (what they can or cannot do anymore), instead of asking about their personal experiences and satisfaction with the situation (Kreitler & Kreitler, 2006). HRQoL may influence individuals' QoL, but it does not represent it (Zubaran & Foresti, 2009). A clear distinction between both concepts should be made when talking about QoL research; the absence of pathology is not the same as having a good QoL (Moons et al., 2006; Cummins et al., 2004; Smith, Avis & Assmann, 1999).
In social sciences, a different view on how QoL should be conceptualised is applied, which is often used in the field of *mental health*. The last two decades, there has been a tremendous change in the way care and support are provided to people with mental disorders and long-term care needs. This is mainly the result of the deinstitutionalisation process in mental health care, including a focus to more community-based support (Katschnig, 2006). A shift from a strict medical model of care has been observed towards a support model that gives a central position to the clients' own perspective and opinion as the starting point of treatment. Empowerment, control and participation of clients are central concepts in this approach. A comparable evolution has been noticed in the field of disability studies (Cummins, 2005). From the 1980's, QoL emerged as an important concept in the support of individuals with intellectual disabilities, with a 'fulfilling citizenship' as the ultimate goal (van Gennep, 1989). This change was mainly based on (1) the limited impact of a purely technocratic approach of treatment, (2) more attention to community-based support and (3) the rise of consumer empowerment with a focus on person-centred planning (Schalock et al., 2002). Nowadays, QoL has been acknowledged as an important outcome measure and useful assessment tool in health care for individuals suffering from chronic illnesses (Katschnig, 2006; Higginson & Carr, 2001; van den Bos & Triemstra, 1999).

1.2.2 What's in a name?!

Notwithstanding the long history of the concept QoL and its recognition as a central concept in health care, there is still no consensus about its definition (Dijkers, 2007; Moons et al., 2006; Carr & Higginson, 2001; Farquhar, 1995). The ongoing debate about the true meaning of the concept, is hindered by the fact that the concept of QoL is used in various disciplines (e.g. medicine, psychiatry, sociology) and has multiple connotations (Farquhar, 1995; Schuessler & Fisher, 1985). Furthermore, many definitions and instruments developed to measure QoL are based on professionals' perceptions about the

concept, while a person's subjective views are often ignored (Carr & Higginson, 2001; Fischer, Rehm & Kim, 2001). The lack of consensus on what QoL constitutes, has been reflected, among other things, in the high number of instruments developed to measure the concept (Vanagas, Padaiga & Subata, 2004) (cf. infra).

In scientific research, a pragmatic approach can be noticed; QoL is often mentioned as an abstract idea, but the meaning of the concept is seldom revealed (Holmes, 2005). A study of Gill and Feinstein (1994) demonstrated that only 15% of the studies in the literature on QoL defined the meaning of this concept. Campbell (1977 in Holmes, 2005) described it as follows*: "A term that everyone understands, but which few can define"*. Despite the lack of a general definition on QoL, two central concepts almost always return: subjectivity and multidimensionality (Costanza et al., 2007; Schalock et al., 2002; Bonomi, Patrick, Bushnell & Martin, 2000). Nowadays, QoL is more and more seen as a broad, holistic concept, which focuses on more than health-related issues, including attention for various aspects of human life (Holmes, 2005; Ruggeri, Gater, Bisoffi, Barbui & Tansella, 2002; Schalock, 1996). It is mainly a subjective concept that represents individuals' perspective and perception on life (Bonomi et al., 2000). 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. Moreover, QoL is a dynamic phenomenon that is influenced by the expectations, hopes and dreams of an individual and his/her ability to fulfil those expectations (Holmes, 2005; Allison, Locker & Feine, 1997; Calman, 1984). Taylor and Bogdan (1996) describe QoL as a *'sensitizing notion'*, in which the primary focus is on a person's own life experiences and values. QoL is defined by the WHO Quality of Life Group as *"individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns"* (The WHOQOL Group, 1998, p. 551).

1.2.3 Methodological issues in measuring QoL

A number of methodological concerns limit the generalisation of QoL data (Zubaran & Foresti, 2009). It is difficult to compare QoL-studies, because of different interpretations of the concept QoL and the use of various types of instruments to measure it. The various ways to measure QoL need to be distinguished.

Subjective and objective measures of QoL

In general, two types of conceptualisation of QoL can be distinguished, namely objective and subjective social indicators (Noll, 2000). The objective social indicators approach is reflected by a certain standard of living, based on normative criteria and uses a number of objective indicators (e.g. unemployment and divorce rates) to talk about individuals' QoL. On the other hand, the subjective QoL approach or psychological indicators approach, is based on the assumption that QoL should be measured by a person's own perspectives and satisfaction with life as a whole and different life domains (Zautra & Goodhart, 1979). This approach goes hand in hand with an upcoming interest for the values, attitudes, beliefs and aspirations of an individual (Rapley, 2003). Abrams (1976 in Farquhar, 1995) formulated the strengths of this approach as follows: "People's perceptions, how uninformed they may be, are real and people act on the basis of them". This subjective approach of QoL, has strongly influenced the conceptualisation of QoL in the field of mental health (cf. supra). Today, there is an overall consensus that QoL consists of both, objective and subjective components of life, although the subjective component of QoL prevails (Schalock et al., 2002; Cummins, 2000). Moreover, there is a poor relationship between objective and subjective aspects of QoL, illustrating the specificity of both approaches (Cummins, 2000; Allison et al., 1997). Currently, there is a consensus in the field of mental health that QoL should encompass both objective and subjective indicators, given the limited correlation between both indicators (Ruggeri, Warner, Bisoffi, & Fontecedro, 2001).

QoL as a unidimensional or a multidimensional concept

QoL can be approached as a unidimensional, global concept, or as a multidimensional construct, based on satisfaction with various life domains (Wu & Yao, 2007). A unidimensional approach of QoL (e.g. "How do you feel about your life as a whole?") is limited to a global assessment of the QoL of an individual, without specific attention to differences in various aspects of life.

This approach is especially useful to compare QoL between various groups in society (e.g. Satisfaction with life scale) (Cummins, 1996). On the other hand, domain-specific assessments measure individuals' satisfaction with various life domains (e.g. WHOQoL), starting from a bottom-up perspective, and provide more concrete information about individuals' experiences with life (Wu & Yao, 2007). This domain-specific approach overrules the problem of 'homeostasis' in overall QoL, as individuals tend to be satisfied if their living conditions are within a certain range, the so-called 'homeostatic system' (Mellor, Cummins, Karlinski & Storer, 2003).

Generally, it is accepted that QoL is influenced by various domains, making a multidimensional approach of the concept desirable (Schalock et al., 2002; Anderson & Burckhardt, 1999). Despite the general agreement that QoL is a multidimensional concept, there is no overall consensus on the number and content of the domains that need to be measured (Holmes, 2005). Researchers suggest that recognizing the multidimensionality of the concept is more important than the specific set of domains being assessed (Bonham et al., 2004). The importance or weight people attach to various dimensions or domains of QoL can differ greatly between individuals and within groups, based on their individual values and priorities, and can fluctuate through their personal course of life (Carr & Higginson, 2001; Carr, Thompson & Kirwan, 1996). Consequently, the multidimensionality of the concept QoL, together with the individualistic nature of the construct may result in a strong heterogeneity and big variation in QoL scores. Given the negative consequences of a drug using lifestyle on various life domains (cf. supra), it will be important to measure opiate-dependent individuals' QoL as a multidimensional concept.

Generic and specific QoL-measures

Finally, we need to distinguish between generic and specific instruments used to measure QoL (Vanagas et al., 2004). Generic measures are not specific for a certain disease and start from the assumption that all diseases have a general impact on individuals' QoL. Therefore, generic instruments are suitable to make comparisons between population groups (Guyatt, Feeny & Patrick, 1993). A limitation of these generic measures is that they lack sensitivity for problems related to a specific group of patients (e.g. cancer, asthma) and for measuring the clinical effects of treatment (Vanagas et al., 2004). Disease-specific instruments are limited to a number of domains relevant for a specific population, while domain-specific instruments involve domains that can be affected by a disease (directly or indirectly), with a focus on the social, psychological and practical consequences of a disease. Consequently, specific QoL-measures are very

relevant in clinical practice to detect changes (Garrat, Schmidt, Mackintosh & Fitzpatrick, 2002).

1.3 Orthopedagogical approach

As a result of my personal training as an orthopedagogue, my research focuses on practice, through the use of various theories, aimed at adults in difficult living situations. Since the establishment of the department of orthopedagogics (1964) at Ghent University, it was never tied down to one dominant paradigm of care (Broekaert, Soenen, Goethals, D'Oosterlinck & Vandevelde, 2008). Orthopedagogics is considered as a scientific discipline, including a practical orientation and a strong direction towards action. It is based on the fruitful interaction of methods and theories from different scientific disciplines (D'Oosterlinck, Goethals, Broekaert, Schuyten & De Maeyer, 2008). This interaction of paradigms underpins the striving for an enhanced QoL in problematic living situations (Broekaert, 2009; Broekaert, D'Oosterlinck, Van Hove & Bayliss, 2004). From this perspective, different paradigms complement each other, without a hierarchy between them. The goal is to carefully examine which paradigm (e.g. empirical-analytical, phenomenological-existential) contributes most to humans' QoL, according to individuals' needs and expectations (Broekaert, Autrique, Vanderplasschen & Colpaert, 2010). QoL starts from a subjective and person-centred approach, which is an integrative part of orthopedagogics (Schalock et al., 2002). Since the concept QoL starts from individuals' own perspectives and regards clients themselves as main actors, attention for individuals' QoL will increase their empowerment and self-control. Empowerment and self-control are both important components in the disability studies, a leading discipline of orthopedagogics (Schalock et al., 2002; Van Hove, 2000). Furthermore, QoL is associated to a certain degree with humanism, with its focus on the strengths of people and its attention to self-actualisation. As a result a humanistic approach is regarded to be a prerequisite for successful orthopedagogical action (Van Hove, 2000). Consequently, QoL provides us with a framework to adjust our way of acting in order to fulfil the needs and interests of an individual (Broekaert et al., 2004).

Attention for the concept of QoL in the orthopedagogical field, was first raised by van Gennep (1989). He formulated strong criticism on the normalisation paradigm and was an advocate of community-based support, personal choice, self-control and QoL of people with disabilities. Due to the subjective character of QoL, one needs to abandon the strict standard of values, typical for our modern society and create space for another way of approaching people, with attention for their own, personal truth.

In this study, some of the shifts experienced in the field of disability studies and mental health research, will be used as a new way of thinking in the field of substance abuse research. By doing so, a shift will be made from a traditional medical perspective in substance abuse research to a more educational perspective, with a focus on acting (Broekaert et al., 2004). An example of a pedagogical approach in substance abuse treatment is the drug-free therapeutic community, based on self-help and social learning (Broekaert & Vanderplasschen, 2003). The introduction of the concept QoL may function as a positive outcome in clinical practice and as a counterpart to the domination of outcomes focussing on pathology and symptom reduction (Frisch, 1998). This will lead to a more pedagogical approach of substance abuse treatment in general. QoL is a useful paradigm that starts from a different perspective, as opposed to the deficit- and problem-oriented approach in health care and social welfare services. This problem-oriented approach is still very prominent in substance abuse research today, while concepts as empowerment, strengths and client perspectives are often unknown territory (Ruefli & Rogers, 2004; Saleebey, 1996). Nevertheless, the concepts empowerment, belonging and self-control are not specific for people with disabilities, but are also extremely useful for meeting the difficulties and deprived situation of individuals dependent on drugs.

From an orthopedagogical standpoint, substance abuse treatment should be based on an integration of paradigms, theories and methods. This will result in an integrated treatment system (e.g. drug-free treatment, substitution treatment, psychiatric services), with a focus on the enhancement of individuals' QoL (Broekaert et al., 2010). Although methadone substitution treatment is regarded as the most effective treatment for opiate dependence, it might be possible (from an orthopedagogical view) that an integration of diverse types of interventions is more suitable to enhance human QoL. Still, it is important to have attention for the unique characteristics of each approach and use them accordingly to fulfil a client's treatment needs (Broekaert & Vanderplasschen, 2003).

The practice-oriented character of this dissertation is a consequence of this orthopedagogical approach. The researcher was strongly embedded in the daily practice of support for opiate-dependent individuals, which was the starting point for this study. Finally, this study is oriented towards action; one of the broader aims of this dissertation is how treatment for opiate-dependent individuals can be adjusted in order to improve individuals' QoL.

1.4 Problem definition and aims of the study

1.4.1 Problem definition

Due to the social consequences of substance abuse, most outcome studies in substance abuse research focus on socially desirable aspects such as termination of drug use, reducing the health risks involved with drug use and the absence of criminal involvement, with limited attention to outcomes important for opiate-dependent individuals themselves (Fischer, Rehm, Kim & Kirst, 2005; Ruefli & Rogers, 2004). Although the results of evaluation studies on the effects of methadone maintenance treatment are mainly positive, there has been a lot of criticism about this one-sided focus on socially desirable outcomes, starting from a utilitarian perspective and the lack of attention to the impact of this treatment on individuals' QoL (Fischer et al., 2005; Barnett & Hui, 2000). In general, research on opiate dependence starts from hard outcome measures, based on the norms and values of society, with limited attention to opiate-dependent individuals' *own perspectives* and values about their life (Fischer et al., 2001). Studies on opiate-dependent individuals' own perspectives on the impact of methadone maintenance treatment on their QoL are almost non-existent. This contrasts sharply with research on other chronic diseases, where clients' perspectives have a prominent place in the evaluation and treatment process (Fischer et al., 2005; Mclellan, 2002; Higginson & Carr, 2001). Nevertheless, research with alcohol-dependent individuals has shown that there is limited resemblance between socially desirable outcomes and individuals' personal feelings of subjective well-being, illustrating the need to involve QoL as an important outcome measure in substance abuse research (Foster, Peters & Marchall, 2000). However, only fragmented and inconsistent information is available on opiate-dependent individuals' QoL.

Second, opiate dependence is more and more considered as a chronic relapsing disorder, affecting various life domains (e.g. unemployment, housing issues, mental illnesses) and resulting in a negative impact on opiate-dependent individuals' daily living situation (Van den Brink & Haasen, 2006; Van den Brink et al., 2003; McLellan, Lewis, O'Brien & Kleber, 2000). The limited curing effects of treatment services for chronic diseases create the necessity to start from a continuing care perspective (WHO, 2004; Mclellan, 2002; O'Brien & McLellan, 1996). However, only a limited number of studies have paid attention to the long-term outcomes of methadone maintenance treatment (Flynn, Joe, Broome, Simpson & Brown, 2003; Hubbard, Craddock & Anderson, 2003) and research on opiate-dependent individuals' QoL several years after starting

treatment is almost non-existent (Hser, 2007; Fischer et al., 2005; Hser, Hoffman, Grella & Anglin, 2001).
The negative and long-term impact of a drug using lifestyle on various life domains urges for a shift of focus in substance abuse research. Attention to treatment outcomes should no longer be restricted to the reduction and elimination of illicit drug use and direct health-consequences, but should start from a *broad perspective*, including the improvement of opiate users' physical and mental health, their social functioning and their overall well-being (WHO, 2009; Fischer et al., 2005). Furthermore, consistent evidence is lacking that improvement of these drug-related aspects contributes to opiate-dependent individuals' QoL. Therefore, the concept of QoL is a broad measure that provides information on the impact of drug use on the different domains of opiate-dependent individuals' life and their overall feeling of well-being.

In conclusion, we can say that clients' perspectives are seldom heard in substance abuse research, even though outcomes based on clients' personal experiences and perspectives would be very useful measures to talk about clinical effectiveness for the benefit of the client (Wiklund, 2004). Furthermore, the focus is mainly on short-term and socially desirable outcomes, with special attention to drug and health-related aspects. If one of the main goals of the care system is to meet clients' needs, it will be inevitable to involve clients in decision-making and to enhance their feelings of empowerment (Kolind, Vanderplasschen & De Maeyer, 2008; Segal, 1998). Consequently, more attention is needed for the subjective perspectives of opiate-dependent individuals themselves, besides the strong focus on socially desirable outcomes.

This dissertation should be seen as an effort to fill some of the gaps in current research and evidence on substitution treatment and opiate dependence, as presented above. With this dissertation we want to place opiate-dependent individuals' QoL in the forefront, and investigate its usefulness as a central assessment and outcome measure in the care and support for opiate-dependent individuals. Therefore, the principal purpose of this study is to raise the knowledge about the concept of QoL in opiate-dependent individuals, starting from *clients' own perspectives*. We believe it is germane to expand our knowledge with the views and experiences of opiate users themselves, in order to understand the real impact of methadone treatment on *their* QoL. By doing so, we want to discourage the ignorance of opiate-dependent individuals' own perspectives. In this study, QoL will be approached as a sensitizing concept that starts from individuals' personal feelings and experiences and that may vary over time and between individuals (Moons et al., 2006; Taylor & Bogdan, 1996).

1.4.2 Aims of the study

The specific aims of this study were fourfold. First, we wanted to explore the concept of QoL as perceived by drug users. There is a lack of information about drug users' perspectives on QoL, and it is a necessity to gain insight in drug users' meaning of the concept, before we can actually start to 'measure' it. There is often a great discrepancy between the issues relevant for the people themselves and the domains being assessed by available quality of life instruments. Second, we intended to evaluate the available research on QoL of opiate-dependent individuals (following substitution treatment), with attention for the comparison with other populations, the influence of substitution treatment on QoL and the impact of potential mediators of QoL. Third, we wanted to offer valid information on the current QoL of opiate-dependent individuals and determinants that influence their current QoL. Although QoL is often mentioned as one of the broader goals of substitution treatment, few information is available on opiate users' QoL and how clinical practice can enhance their QoL. Without accurate information on what constitutes opiate-dependent individuals' QoL and how it can be influenced, we cannot expect that treatment is able to improve the QoL of this group of people. Finally, the impact of methadone substitution treatment and its influence on aspects of a good QoL are addressed.

1.5 Specific research questions and research design

1.5.1 Specific research questions

The aims of this dissertation were crystallised in specific research questions in 4 separate studies.

- *How do substance abusers perceive the concept QoL?*

In a *first study*, our goal was to identify how a broad group of drug users perceives and understands the concept QoL. Between September and November 2007, focus groups were used as a method to gain information on drug users' perceptions about important domains of QoL. The starting point of this study were clients' perspectives. The data of this study came from nine focus group discussions with in total 67 drug users, who were recruited in various treatment settings and community services in Flanders. Afterwards, the results of the focus groups were compared with the core dimensions of the theoretical framework on QoL of Schalock (1996), to see if this framework was also applicable among

substance abusers. The results of this explorative study are reported in chapter 2 of this dissertation.

- *What available evidence exists on opiate-dependent individuals QoL?*

In a *second study*, the focus was narrowed to opiate-dependent individuals. We performed a systematic review of the literature, based on studies published between 1993 and 2008 in peer-reviewed journals (*Chapter 3*). A distinction was made between studies focussing on QoL and HRQoL. Specific attention was given to the following research questions: "Which instruments are used to measure opiate-dependent individuals' QoL?", "Is opiate-dependent individuals' QoL comparable with that of other populations (general population, other chronic diseases)?", "What is the impact of substitution treatment on QoL and are there differences noticeable between different forms of substitution treatment?", and finally, "What are potential mediators or determinants of opiate-dependent individuals' QoL?". Limitations of existing studies on QoL with opiate users were discussed and were considered as aspects that needed attention in our own quantitative study.

- *What is the current QoL of opiate-dependent individuals who started methadone maintenance treatment at least five years ago? Is there a link between socially desirable outcomes (e.g. current heroin use) and QoL? Which demographic, psychosocial, drug and health-related variables determine QoL?*

The *third study* formed the core part of this dissertation with an in-depth exploration of opiate-dependent individuals current QoL and the factors influencing it. In this quantitative study, we wanted to address the lack of (long-term) research on the current QoL of opiate-dependent individuals, who started an outpatient methadone treatment at least five years ago. Furthermore, we wished to explore the correlation between a number of potential determinants of QoL on both total and domain-specific QoL. This study was set up as a cross-sectional study on the current QoL of a cohort of opiate-dependent individuals who started outpatient methadone treatment in the region of Ghent (East-Flanders, Belgium) between 1997 and 2002. This period was chosen, since the first medical-social care centre for outpatient methadone treatment was opened in 1997 in Ghent (cf. supra) and since we intended to monitor the current situation of opiate-dependent persons who started methadone treatment during the first six years. Not only clients who followed methadone treatment in the medical-social care centre were eligible for the study, but methadone could also be supplied by general practitioners, outpatient clinics (e.g. day-care centre De Sleutel) and

private psychiatrists. Inclusion criteria for this study were: being over 18 years and opiate-dependent at the start of an outpatient methadone treatment and having started this treatment in the region of Ghent between January 1997 and December 2002. There were no restrictions on treatment duration, in order to avoid treatment bias. In total, 159 subjects participated in this quantitative study between March 2008 and August 2009. Clients who were currently in methadone treatment, as well as those no longer in treatment (25.8%), were included in the study.

Opiate-dependent individuals' QoL was measured by use of the Lancashire Quality of Life Profile, commonly used in mental health research. The findings of our study on the conceptualisation of QoL (*Chapter* 2) have largely determined the choice of our QoL-instrument, used in this quantitative study. By doing so, we wanted to start from a bottom-up approach, based on drug users' own voices and their perception on QOL. In addition, we decided to screen this population on current psychological distress by use of the Brief Symptom Inventory, given the high occurrence of psychological problems in opiate-dependent individuals. Furthermore, the EuropASI was administered to gain insight in the severity of substance use and related problems. Since we were interested in opiate-dependent individuals' own perspectives about methadone treatment, the Verona Service Satisfaction Scale for Methadone Treatment was administered to assess their satisfaction with treatment. The questionnaires used in this study have shown a good reliability and validity, also when used with opiate-dependent individuals.

The results of this quantitative part of this dissertation are described in chapter 4 and 5. In chapter 4, the current satisfaction with life of opiate-dependent individuals on various domains is investigated, with special attention for domains with low (problem areas) and high QoL-scores (strengths). By use of a multiple linear regression model, the independent impact of various determinants on total QoL is assessed. In chapter 5, attention is given to domain-specific determinants of QoL, in order to assess the multidimensional character of the concept. Given the chronic character of opiate dependence and high rates of relapse, the impact of current heroin use on QoL was further investigated. Path analyses were used to examine potential indirect effects of current heroin use on domain-specific QoL (*Chapter 5*).

- *What is the impact of methadone on important components of QoL?*

A *fourth study*, was carried out with a sub-sample of the quantitative study. Between September 2008 and August 2009, 25 opiate-dependent individuals participated in open-ended interviews, starting from their own narratives. Attention was given to the phenomenology of QoL itself, without starting from

certain assumptions about the interpretation of the concept. Idiographic assessment that takes into account the uniqueness of an individual and highlights the distinctiveness of each case was therefore suitable. Personal narratives were used to assess and discuss the richness and diversity of individuals' experiences about components of a good life and more in particular their experiences with methadone in their daily life. By asking opiate-dependent individuals about their best period in their life since starting methadone treatment, this study starts from a strengths perspective, rather than a problem-oriented approach (which is very typical in substance abuse research). The impact of methadone treatment on important components of individuals' lives is discussed, with attention to a holistic approach and the associations between various aspects of a good QoL.
At the end of this dissertation (*Chapter 7*), a general discussion provides the reader with an overview of the main findings of this study, the limitations and implications for clinical practice and future research.

1.5.2 Research design

Based on the orthopedagogical ground of this dissertation, we chose for an integration of different methodological approaches, all with their own specific value. This is in strong contrast with the methodocentric point of view, which starts from one specific paradigm or method (Broekaert et al., 2010). Consequently, in order to answer the aims of this study and to improve construct validity, we have chosen for a mixed methods approach to gain insight in the phenomena investigated in this dissertation (Fountain & Griffiths, 1999; Cowman, 1993). Consequently, limitations of individual methods were counterbalanced and the effects of researcher bias were reduced. Methodological triangulation was applied by using both, qualitative and quantitative methods, but also by using different qualitative methods (focus groups and open interviews) (Dale, 1995). By use of a mixed method approach the goal was not only to confirm results by using both quantitative and qualitative methods, but also to gain more insight and in-depth understanding of the concept of QoL (among opiate-dependent individuals) (Camfield, Crivello & Woodhead, 2009; Dunning, Williams, Abonyi & Crooks, 2008; Neale, Allen & Coombes, 2005). In this study, we also start from a multivariate design, rather than a between-groups approach. The focus is on determinants of QoL, with attention to the contextual nature and the complexity of the concept QoL (Schalock, Bonham & Marchand, 2000).

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Chapter 2

Exploratory study on drug users' perspectives on quality of life: More than health-related quality of life?[1]

[1] Based on De Maeyer, J., Vanderplasshen, W., & Broekaert, E. (2009). Exploratory study on drug users' perspectives on quality of life: More than health-related quality of life? Social Indicators Research, 90(1), 107-126.

Abstract

Objective: 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. Still, Quality of Life (QoL) has become an important concept to evaluate effectiveness of treatment in mental health care research and disability studies. Given the limited and 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.

Methods: 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 (1996).

Results: 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.

Conclusion: 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.

2.1 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 & Chen, 2004), while rates of alcohol and illicit drug use among the adult population in the EU vary between 4 and 12 percent, 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, Rehm & Kim, 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 (Fischer, Rehm, Kim & Kirst, 2005; Barnett & Hui, 2000). 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, Peters & Marchall, 2000).

2.1.1 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 & 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, Locker & Feine, 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 further 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.

2.1.2 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 (McLellan, Lewis, O'Brien & Kleber, 2000; Brindis & Theidon, 1997). 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 (Smith & Larson, 2003; Torrens et al., 1997). 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) (McLellan, Cacciola, Alterman, Rikoon & Carise, 2006; Giacomuzzi et al., 2005; Smith & Larson, 2003). They also give a comprehensive view of persons' situations, not only focusing on problems and disabilities but also looking for strengths and resources (Maremmani, Pani, Pacini & Perugi, 2007; Saleebey, 1996).

Most studies that have assessed QoL among substance users remain limited to aspects of health-related QoL (HRQOL) (De Jong, Roozen, van Rossum, Krabbe & Kerkhof, 2007; Rudolf & Watts, 2002; Garg, Yates, Jones, Zhou & Williams, 1999; Torrens et al., 1997), despite the fact that several authors have demonstrated that QoL is a broader and therefore more useful concept (Cummins, 2005; Schalock, 1996; Boevink, Wolf, van Nieuwenhuizen & Schene, 1995). HRQOL is a subjective measure of persons' mental and physical health and its influence on their functional status (Mooney, 2006; Millson et al., 2004; Farquhar, 1995). It mainly answers the question 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 & Larson, 2003; Stein, Mulvey,

Plough & Samet, 1998), but this improves once alcohol consumption is reduced (Foster, Powell, Marshall & Peters, 1999). Other authors have also demonstrated a negative effect of psychotropic drug use on QoL (Ventegodt & Merrick, 2003, Stein et al., 1998), 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 & Larson, 2003). Factors that influence drug and alcohol users' QoL negatively are heavy alcohol use and infectious diseases (Costenbader, Zule & Coomes, 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 three months of treatment (Senbanjo, Wolff & Marshall, 2006; Torrens et al., 1997), but these effects tend to decrease over time (Giacomuzzi, Kemmler, Ertl & Riemer, 2006; Habrat, Chmielewska, Baran-Furga, Keszycka & Taracha, 2002).

The concept of QoL

QoL is an overarching concept, which has often been applied in health care research (Padaiga, Zubata & Vanagas, 2007), particularly in the fields of disability studies and mental health care (Masthoff, Trompenaars, Van Heck, Hodiamont & De Vries, 2005; Schalock, 2005). Nevertheless, there is controversy over the meaning of this concept, and there is no consensus about its definition (Moons, Budts & De Geest, 2006; Taillefer, Dupuis, Roberge & Le May, 2003; Carr & Higginson, 2001; Fischer et al., 2001a, b;). Various professions create their own interpretations, with little resemblance and much fragmentation in-between disciplines (Rapley, 2003; Farquhar, 1995). 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 (Giacomuzzi et al., 2003; Carr & Higginson, 2001; Foster et al., 2000; Allison et al., 1997; Oliver, Huxley, Priebe & Kaiser, 1997; Torrens et al., 1997).

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

In general, there is a poor correlation between objective and subjective measurements of QoL (Cummins, 2000; Foster et al., 2000; Allison et al., 1997; Edgerton, 1996). Only when objective QoL is very low 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, Cummins, Karlinski & Storer, 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, Brown & Fry, 1994), but QoL is mainly determined by the perception of the individual (Schalock & 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 gives a sense 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 & Bogdan, 1996). Consequently, QoL may vary substantially between individuals and will be influenced by someone's specific life situation (Taylor & Bogdan 1996; Farquhar, 1995). 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 (Carr & Higginson, 2001; Foster et al., 2000; Allison et al., 1997). 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 & 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 & Higginson, 2001; Taylor & Bogdan, 1996).

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 & 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 & 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, Thompson & Kirwan, 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 (Vanderplasschen & De Maeyer, 2007; Brun & Rapp, 2001). 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 literature (Drumm et al., 2003; Brun & Rapp, 2001; Hunt & 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, Polinsky, Maglione & Anglin, 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 & Barker, 1999).

2.2 Methods

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 & 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 & 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, Jones, Kearns & Ward, 1996).

2.2.1 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 2.1** provides an overview of the characteristics of the 9 focus groups, including the setting and the number and age range of the participants.

2.2.2 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 '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 minutes, 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.

Table 2.1: Characteristics of project focus groups

Name and number of the focus group needs	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 psychosocial 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

2.2.3 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 of the 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 (Vandevelde, Vanderplasschen & Broekaert, 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., 1995; Masthoff et al., 2005; Schalock & Verdugo Alonso, 2002). All eight 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 eight domains, the researcher added these missing domains to the discussion. There was also the possibility 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.

2.3 Results

Below, the most important themes and their implications that resulted from the focus groups 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 2.2** indicates how the domains were operationalised for this study.

2.3.1 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 but 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 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' 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).

Table 2.2: Operationalisation of Schalock's (1996) QoL domains

Domain	Indicators
1. 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
2. Social inclusion	Social participation Safe environment Structure Hobbies Work Key barriers: social pressure; limited possibilities; boredom; stigma; clean record
3. Personal development	Discovering abilities Skills Education
4. Self-determination	Goals and challenges Making own choices Independence Structure External control
5. Rights	Concrete rights: housing; medical assistance; food Abstract rights: second chance; new start; privacy; freedom of speech; right to say no Deprived rights Duties
6. Emotional well-being	Inner rest Identity Find balance and set boundaries Time to change Coping Self-esteem
7. Material well-being	Housing Work Transport Financial security Paperwork
8. Physical well-being	Health care Sleep Well-balanced food Sports Appearance and hygiene Self-care Drug-related problems: needle exchange; vaccinations; individualised care; consumption rooms

2.3.2 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 hours 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 basket maker, 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.

2.3.3 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, 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.

2.3.4 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)

2.3.5 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 persons reported some specific rights, such as housing, medical assistance and food. Other rights are rather 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.

2.3.6 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 to be completely happy and to still 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 further been developed."* (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)

2.3.7 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 comfort 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)

2.3.8 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 (e.g. abscesses, gastro-enteric problems, lung diseases, reduced resistance) are evaluated as crucial, such as vaccination and needle exchange programs.

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) 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)

2.4 Discussion

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 (Cummins, 2005; Schalock & Verdugo Alonso, 2002; Boevink et al., 1995). In the following section, we explore this connection further.

2.4.1 More than health-related quality of life

The most common themes that drug users related with 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 & 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 & 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, Schene & Koeter, 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 & 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 & 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, empowerment and a strengths approach in this field (Saleebey, 2007). 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 unicity and multiplicity of clients' problems and helps them to link with needed services (Rapp 2007; Vanderplasschen, Rapp, Wolf & Broekaert, 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 & 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.

2.4.2 Between-group differences

In general, there was agreement that the eight 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 & 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 & 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 the 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, Padaiga & Bagdonas, 2006). Treatment should be based on clients' needs (rather than on the supply or offer available), 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 & 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 own life. 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.

2.4.3 Limitations of the study

Some methodological limitations of this study should be taken into account. First, focus group results cannot be generalized and they rather 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, 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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Chapter 3

Quality of life among opiate-dependent individuals: A review of the literature[2]

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[2] Based on De Maeyer, J., Vanderplasschen, W., & Broekaert, E. (2010) Quality of life among opiate-dependent individuals: A review of the literature. *International Journal of Drug Policy (21)*5, 364-380.

Abstract

Objective: Quality of life (QoL) has become an important outcome indicator in health care evaluation. A clear distinction has to be made between QoL – focussing on individuals' subjective satisfaction with life as a whole and different life domains – and health-related QoL (HRQoL), which refers to the absence of pathology. As opiate dependence is the primary drug of most persons entering treatment and as the attention for QoL in addiction research is growing, this review of the literature intends to summarise and differentiate the available information on QoL in opiate-dependent individuals.

Methods: A comprehensive literature review was conducted, including database searches in Web of Science, Pubmed and Cochrane Database of Systematic Reviews. Articles were eligible for review if they assessed QoL or HRQoL of opiate-dependent individuals, used a QoL or HRQoL instrument and reported at least one specific outcome on QoL or HRQoL.

Results: In total, 38 articles have been selected. The review showed that various instruments (n = 15) were used to measure QoL, mostly HRQoL instruments. Opiate-dependent individuals report low (HR)QoL compared with the general population and people with various medical illnesses. Generally, participation in substitution treatment had a positive effect on individuals' (HR)QoL, but long-term effects remain unclear. Psychological problems, older age and excessive alcohol use seem to be related with lower (HR)QoL scores.

Conclusion: The assessment of QoL in research on opiate dependence is still in its infancy. Still, the chronic nature of drug use problems creates the necessity to look at outcomes beyond the direct consequences of drug dependence and based on clients' needs. HRQoL, with its unilateral focus on the functional status of clients, does not give information on clients' own experiences about the goodness of life, and is as a consequence unsuitable for measuring QoL. Future research starting from a subjective, multidimensional approach of the concept of QoL is required.

3.1 Introduction

3.1.1 Quality of life and health-related QoL: two different constructs

Patients' self-reported outcomes (e.g. quality of life) have become an increasingly important source of information in health care. This has been helped by a focus on the empowerment of help-seeking individuals (Segal, 1998) and the prevalence of various chronic illnesses (Guyatt et al., 2007; Smith, Avis, & Assmann, 1999). The limited curing effect of treatment services for chronic diseases such as diabetes and depression, for example, has created the need for long-term treatment and a shift from cure to care, with attention to the patients' perspectives (Wiklund, 2004). The best known patient-reported outcome is quality of life (QoL) (Valderas et al., 2008; Winklbaur, Jagsch, Ebner, Thau, & Fischer, 2008). During the last decades various disciplines have focused on QoL (Bowling & Brazier, 1995), however, the concept is vague and its use inconsistent (Dijkers, 2007; Skevington, Lofty, & O'Connell, 2004; Smith et al., 1999; Farquhar, 1995). Researchers often consider terms like 'health status' and 'health-related quality of life' (HRQoL) as synonymous with QoL (Muldoon, Barger, Flory, & Manuck, 1998), resulting in the inconsistent use of the concept (Gill, Alvan, & Feinstein, 1994). HRQoL has its foundations in a definition of health from 1947 (Cummins, Lau, & Stokes, 2004) and this contrasts sharply with subjective well-being or subjective QoL. It measures the effects of a disease on individuals' everyday functioning, with special attention given to physical and psychological limitations (Burgess et al., 2000). HRQoL is frequently used in general medicine to demonstrate the absence of pathology. In social sciences and psychiatry, on the other hand, there is a strong focus on respondents' reported satisfaction with life as a whole, including a multidimensional or holistic approach to the concept of QoL (Cummins et al., 2004; Van Nieuwenhuizen, Schene,&Koeter, 2002). Several authors (Katschnig, 2006; Schalock & Verdugo Alonso, 2002) have demonstrated the importance of individuals' own perceptions in conceptualising QoL and approach QoL as a 'sensitising concept' – starting from individuals' subjective experiences – rather than as a definite construct with a fixed definition. Consequently, we will make a distinction here between HRQoL and subjective QoL and indicate how Quality of Life was conceptualised in each study. When referring to both HRQoL and subjective QoL the term (HR)QoL is used. We need to distinguish between two types of instruments developed to measure QoL – 'generic' and 'specific'. 'Generic' measures (e.g. SF-36; WHOQoL) can be widely applied across populations and pathologies, allowing a comparison between different groups (Vanagas, Padaiga, & Subata, 2004; Garrat, Schmidt, Mackintosh, & Fitzpatrick,

2002); 'specific' measures focus on a specific population, disease, function or problem (e.g. Lancashire QoL profile) (Vanagas et al., 2004; Guyatt, Feeny, & Patrick, 1993). Another distinction can be made between 'global' and 'domain-specific' instruments (Wu&Yao, 2007). A 'global' approach (e.g. satisfaction with life scale) assesses QoL in an overall manner (unidimensional), leading to one global score based on limited items. 'Domainspecific' measures consider various life domains at the same time (e.g. subjective quality of life profile) and produce subscores for different domains (multidimensional). Therefore, researchers need to be aware of these conceptual and methodological issues and clarify what they mean (Dijkers, 2007) before choosing an instrument to measure QoL.

3.1.2 QoL in addiction research

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 (Neale, Sheard, & Tompkins, 2007). Traditionally, evaluation studies start from a unilateral focus based on the norms and values of society, instead of listening to drug users' own personal experiences (Stajduhar, Funk, Shaw, Bottorff, & Johnson, 2009; Fischer, Rehm, & Kim, 2001). In general, attention is mostly given to socially desirable outcomes (e.g. no drug use, work, no criminal involvement) (Fischer, Rehm, Kim,&Kirst, 2005; Mattick et al., 2003; Ward, Hall, & Mattick, 1999) and health-related outcomes (e.g. preventing infectious diseases) (Farrell, Gowing, Marsden, Ling,&Ali, 2005; Verrando, Robaeys, Mathei, & Buntinx, 2005). Until the 1990s, only limited attention was given to QoL in the addiction research field. This was in contrast to the large number of randomised controlled trials reporting on QoL research into other chronic illnesses, such as cancer and cardiovascular diseases (Sanders, Egger, Donovan, Tallon, & Frankel, 1998). One of the first studies of QoL among drug users by Ryan and White (1996) showed that the HRQoL of heroin users starting treatment was significantly worse than the general population and most comparable with individuals with psychiatric disorders. Torrens et al. (1997) observed a noticeable improvement of HRQoL among persons in methadone maintenance treatment (MMT), especially during the first month of treatment. A review of these early QoL studies (up to 2000) among alcohol and drug users (Rudolf & Watts, 2002) did not allow general conclusions due to the small number of studies and the use of different constructs (HRQoL and QoL) and instruments. Since 2000, interest in QoL in addiction research –mainly among opiate users – has grown extensively. This goes hand in hand with the recognition that substance misuse is a chronic, relapsing disorder that may have negative consequences for various life domains

(Vanderplasschen, Rapp, Wolf, & Broekaert, 2004; Rudolf & Watts, 2002; McLellan, Lewis, O'Brien, & Kleber, 2000). Relapse has been identified as a rule rather than an exception, especially among opiate-dependent persons (Vanderplasschen et al., in press; Van den Brink & Haasen, 2006; Van den Brink, Goppel, & van Ree, 2003).

3.1.3 Aim of the study

Despite the limitations mentioned above, QoL is an important indicator not captured by traditional and objective outcome measures and it can be used to tailor drug policy and treatment to drug users' needs. Opiates remain the primary drug for the majority of those entering treatment (EMCDDA, 2008), and although the number of opiate-dependent individuals remains high (Kleber, 2005), only fragmented and often conflicting information on their QoL is available. A comprehensive review was needed to summarise the literature on QoL among opiate users and to set priorities for future QoL research. Here the aim was to compare studies that have explored the (HR)QoL of opiate-dependent individuals and to assess the instruments used to measure (HR)QoL. First, we focused on studies that have compared opiate users' (HR)QoL with the general population or other control group. Second, we assessed the influence of substitution treatment (e.g. methadone, buprenorphine) on (HR)QoL. Finally, the influence of potential mediators (e.g. gender, age, drug use, psychiatric comorbidity) on (HR)QoL was evaluated.

3.2 Methods

A comprehensive literature search was undertaken of databases such as ISI Web of Science, Pubmed/Medline, Cochrane Database of Systematic Reviews and Drugscope. The following terms were entered and combined as keywords: 'addiction/substance (ab)use/drug (ab)use', 'quality of life/health-related quality of life/health status/satisfaction with life' and various opiate drugs such as 'heroin', 'methadone' and 'buprenorphine'. Reference lists of the retrieved articles and grey literature were carefully screened for additional studies. Articles were included in the review if they met the following inclusion criteria: (1) Studies needed to assess (HR)QoL among individuals with opiate dependence. Studies about people with other substance use problems (e.g. alcohol or cocaine) or with other chronic diseases (e.g. hepatitis, HIV, personality disorders) were included if opiate dependence was present among at least one subsample of the study and if data about this group were reported separately. (2) Articles were further eligible if they used an instrument to measure (HR)QoL and (3) reported at least one specific outcome on (HR)QoL. (4) However, these instruments had

to be completed by clients themselves, not by proxies or clinicians. All such articles were included if they were published before 2009. All abstracts were independently reviewed by two of the authors.

In total 127 articles were retrieved. Of those 89 were excluded because their focus was on users of non-opiate drugs (n = 83), they did not use a specific (HR)QoL instrument (n = 3), they did not report specific (HR)QoL outcomes (n = 2) or opiate users were not dealt with as a separate group (n = 1).

Thirty-eight studies – published between 1993 and 2008 – met the inclusion criteria, using a total of 15 instruments to measure (HR)QoL (cf. **Table 3.1**).Two studies used two different instruments to measure (HR)QoL (De Jong, Roozen, van Rossum, Krabbe, & Kerkhof, 2007; Dunaj & Kovác, 2003). There were only three papers detailing randomised controlled trials. Five studies were published by the same principal author (Giacomuzzi, Kemmler, Ertl, & Riemer, 2006; Giacomuzzi, Ertl, Kemmler, Riemer, & Vigl, 2005; Giacomuzzi, Riemer, et al., 2005; Giacomuzzi et al., 2001, 2003), all using the same instrument, but comparing various subsamples on specific outcomes regarding subjective QoL.

Given the strong heterogeneity of the retrieved studies (e.g. sample size, instruments used, conceptualisation of QoL), it was impossible to carry out a meta-analysis of QoL outcomes. Therefore, a narrative review was performed, taking into account the variability of study design and conceptualisation of QoL (cf. **Diagram 3.1**). One study included a cross-sectional and a longitudinal analysis, resulting in 16 longitudinal and 23 cross-sectional studies. The follow-up period for observation ranged from three months to three years. Four of the 23 cross-sectional studies compared outcomes with the general population as well as across different treatment modalities, resulting in a higher number of studies between the third (n = 27) and the second level (n = 23) of the diagram.

Table 3.1: Overview of instruments (*n* = 15) used to measure QoL in the selected articles

Name of instrument	Conceptualisation	Applied QoL-measures	Number of studies
1. Comprehensive quality of life scale – adults (ComQol-A5) (Cummins et al., 1994)	Generic QoL instrument	35 items 7 domains: material well-being, health, productivity, intimacy, safety, place in community, emotional well-being Objective and subjective components for each domain Measures domain satisfaction and importance Overall QoL score and 7 domain scores (5-point scale for importance and 7-point scale for satisfaction)	**1 study**: Dunaj and Kovác (2003)
2. EuroQoL-5D (Brooks, EuroQoL Group, 1996)	Generic HRQoL instrument	14 items 5 domains: mobility, self-care, daily activities, pain, depression Overall QoL score, based on population norms and on patient ratings (visual analogue scale 0–100)	**1 study**: De Jong et al. (2007)
3. Lancashire QoL profile (Oliver et al., 1997)	Specific QoL instrument for persons with mental health problems	105 items 9 domains: work and education, living situation, leisure time, religion, finances, law and security, family relations, social relations and health Overall QoL score and 9 domain scores (7-point scale)	**7 studies**: Winklbaur et al. (2008), Giacomuzzi et al. (2006), Giacomuzzi, Ertl, et al. (2005), Giacomuzzi, Riemer, et al. (2005), Giacomuzzi et al. (2003), Giacomuzzi et al. (2001) and Fischer et al. (2000)
4. McGill quality of life questionnaire (Cohen et al., 1995)	Specific QoL instrument for persons with life-threatening illnesses	16 items 4 domains: physical well-being, psychological symptoms, existential well-being and support Overall QoL score and 4 domain scores (range 0–10)	**1 study**: Fassino et al. (2004)
5. Nottingham health profile (NHP) (Hunt et al., 1981)	Generic HRQoL instrument	38 items 6 domains: energy, pain, emotional reactions, sleep, social isolation and physical mobility	**2 studies**: Puigdollers et al. (2004) and Torrens et al. (1997)

		Overall QoL score and 6 domain scores (range 0–100)	
6. Quality of life enjoyment and satisfaction questionnaire (Q-LES-Q) (Endicott et al., 1993)	Specific QoL instrument for persons with mental health problems	93 items 8 domains: satisfaction with physical health, feelings, work, household duties, school, leisure-time activities, social relationships and general activities Overall QoL score and 8 domain scores (5-point scale)	**1 study**: Ponizovsky and Grinshpoon (2007)
7. Quality of life questionnaire (QOLQ) (Bigelow et al., 1991)	Specific QoL instrument for persons with mental health problems	109 items 10 domains: job, leisure, appetite, sleep, social relationships, social involvement, income, parental role, romantic relationships and self-acceptance Overall QoL score and 10 domain scores (range 0–50)	**1 study**: Maremmani et al. (2007)
8. Satisfaction with life scale (SWLS) (Diener et al., 1985)	Generic QoL instrument	5 items Overall QoL score (7-point scale)	**1 study**: Luty and Arokiadass (2008)
9. Self-developed instrument (Eklund et al., 1994)	QoL assessment, no further information available	7 items 7 domains: family situation, child situation, housing situation, occupational situation, leisure situation, involvement with drug subculture and drug situation 7 domain scores (5-point scale)	**1 study**: Eklund et al. (1994)
10. Self-developed instrument (Reno & Aiken, 1993)	QoL assessment, no further information available	4 items No further information available	**1 study**: Reno and Aiken (1993)
11. SF-36 (Ware & Sherbourne, 1992)	Generic HRQoL instrument	36 items 8 domains: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, mental health 2 summary scores ‘physical health’ and ‘mental health’ and 8 domain scores (range 0–100)	**13 studies**: Karow et al. (2008), De Jong et al. (2007), Hser (2007), Millson et al. (2006), O’Brien et al. (2006), Villeneuve et al. (2006), Haug et al. (2005), Lofwall et al. (2005), Deering et al. (2004), Millson et al. (2004), Habrat et al. (2002), Rooney et al. (2002) and Ryan and White (1996)

12. SF-12 (Ware et al., 1996)	Generic HRQoL instrument	12 items Short-form of the SF-36 Same domains and scores as SF-36	**4 studies**: Astals et al. (2008), Rosen et al. (2007), March et al. (2006) and Senbanjo et al. (2006)
13. Subjective quality of life profile (Gerin et al., 1991)	Generic QoL instrument	36 items 4 domains: health, social relationships, material and spiritual/inner life Measures satisfaction, importance and future expectations for each item Overall QoL score and 4 domain scores (5-point scale for satisfaction and expectations and 4-point scale for importance)	**1 study**: Dazord et al. (1998)
14. Tableau d'Évaluation Assistée de la Qualité de Vie (TEAQV) (Grabot et al., 1996)	Specific QoL instrument for persons with chronic psychiatric and somatic diseases	4 items 4 domains: physical well-being, psychological well-being, family relationships and professional activity Measures prospective and retrospective QoL 4 domain scores (7-point scale)	**1 study**: Vignau and Brunelle (1998)
15. WHOQoL Bref (Harper & Power, WHOQOL Group, 1998)	Generic QoL instrument	26 items 4 domains: physical, psychological, social relationships and environmental domain Overall QoL score and 4 domain scores (5-point scale)	**4 studies**: Lawrinson et al. (2008), Padaiga et al. (2007), Bizzarri et al. (2005) and Dunaj and Kovác (2003)

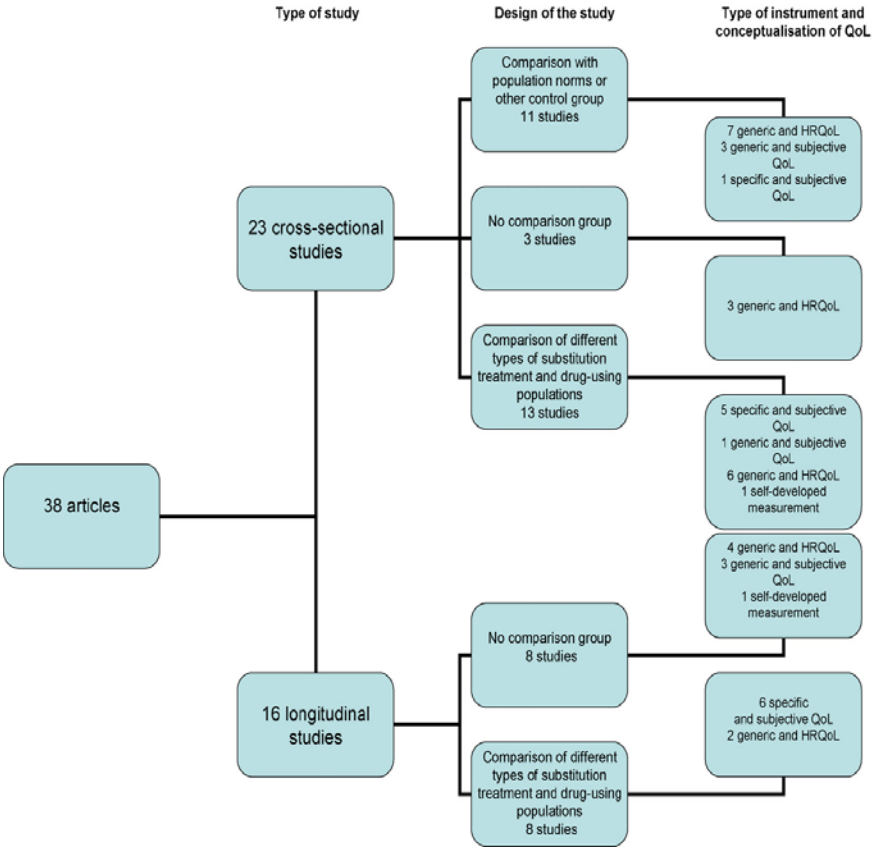

Diagram 3.1. Overview of the type and design of the selected studies and conceptualisation and type of instrument used to measure QoL

3.3 Results

3.3.1 Conceptualisation and measurement of QoL

Instruments that measure QoL can be used for various purposes, such as comparing the QoL of subgroups or measuring changes in QoL (Guyatt et al., 1993). Most of the selected studies (n = 21) either used (HR)QoL as an outcome measure to compare the effectiveness of one type of substitution treatment among various subgroups of opiate-dependent persons or made the comparison between various substitution treatments (e.g. methadone, buprenorphine). Other studies (n = 11) have assessed the current (HR)QoL of opiate users as compared with a control group (e.g. 'normal' population, psychiatric patients, ...); eight studies observed the long-term effects of substitution treatment on (HR)QoL;

and three studies focused primarily on the influence of mediators on (HR)QoL. **Table 3.2** gives an overview of the studies that were included.

Both constructs – QoL and HRQoL – have been used in research on QoL among opiate-dependent individuals, with slightly more studies assessing HRQoL. A subjective approach to QoL was applied slightly more in the longitudinal studies. Notably, all specific instruments (cf. Table 1) – most of which were developed for use among mental health populations – took a multidimensional approach to QoL.

Generic instruments were used to measure both constructs, although generic measures were more often used to assess HRQoL. Surprisingly, studies that measure the (HR)QoL of opiate-dependent persons tended to use generic measures, with no attention to disease or population-specific dimensions. The SF-36, a widely used generic HRQoL instrument (McHorney, Ware, & Raczek, 1993), was applied in 17 studies. It is possible that generic measures (e.g. SF-36) are not sensitive enough to measure change among specific populations (Garrat, 2009; Guyatt et al., 1993).

3.3.2 QoL of opiate users as compared with other populations

Generally, opiate-dependent individuals – at the start of treatment as well as during treatment – report a significantly lower HRQoL compared with the general population or a comparison group (cf. Table 2). Differences were most obvious in the domains 'social functioning', 'physical and emotional role limitations', 'general health' and 'mental health' (Deering et al., 2004; Millson et al., 2004; O'Brien et al., 2006). In the studies by Ryan and White (1996) and Millson et al. (2004), the HRQoL of opiate-dependent individuals was compared with that of patients with minor medical, major medical and psychiatric problems. Despite the fact that drug use is often associated with poor physical health, opiate-dependent individuals had better scores for 'physical functioning' than all three comparison groups. Furthermore, opiate-dependent persons' scores were most comparable with those with psychiatric problems, although they scored worse for 'general health' and 'social functioning' (Ryan & White, 1996). Their poor scores for 'mental health' might be explained by the high prevalence of comorbid psychiatric disorders among drug users (Callaly, Trauer, Munro, & Whelan, 2001; Rodríguez-Llera et al., 2006).

The above studies all focus on HRQoL by using a version of the SF-36, but a limited number of studies (Dunaj & Kovác, 2003; Fassino, Abbate Daga, Delsedime, Rogna, & Boggio, 2004; Bizzarri et al., 2005; Luty & Arokiadass, 2008) also reported significantly worse scores for subjective measures of QoL compared with a control group or the general population.

Table 3.2: Overview of all included studies (*n* = 38) that have measured (HR)QoL among opiate-dependent individuals; only results on (HR)QoL are reported; the sample is described in the original authors' language

Authors + place	Study design	Sample	Instrument	Main outcomes
1. Reno and Aiken (1993); Arizona, USA	Longitudinal, follow-up after 2 and 8 months	Heroin addicts entering methadone maintenance treatment (*n* = 219)	Self-developed instrument	QoL increased significantly during the 2 months following treatment entry
2. Eklund et al. (1994); Stockholm, Sweden	Cross-sectional	Methadone patients trying to stop methadone treatment (*n* = 50) Comparison of persons who terminated methadone treatment (*n* = 25) and those who failed to do so (*n* = 25)	Self-developed instrument	Higher QoL among the group that was successful in terminating methadone maintenance treatment
3. Ryan and White (1996); Adelaide, Australia	Cross-sectional	Heroin users entering methadone maintenance treatment (*n* = 100) Comparison of this sample with UK population norm and patients with minor medical, major medical and psychiatric problems	SF-36	Significantly worse HRQoL scores on all 8 domains of the SF-36 as compared with general population Significantly worse HRQoL scores among heroin users as compared with subjects with minor and major medical conditions Heroin users' scores were most comparable with individuals with psychiatric problems Positive impact of alcohol and cannabis use on HRQoL
4. Torrens et al. (1997); Barcelona, Spain	Longitudinal, follow-up after 1, 3, 6 and 12 months	Opiate-dependent subjects entering methadone maintenance treatment (*n* = 135)	Nottingham health profile (NHP)	Significant improvements on all 6 domains of the NHP during the 1st month of treatment Improvements between the 3rd and 6th, and 6th and 12th month persisted, but were no longer significant
5. Dazord et al. (1998); Geneva, Switzerland	Longitudinal, 12-month follow-up	Heroin-dependent subjects entering methadone maintenance treatment (*n* = 102)	Subjective quality of life profile	Poor satisfaction profile before treatment Persons still in MMT after one year showed significant improvements on 21 of the 36 items Their expectations about aspects of life decreased significantly Higher initial expectations were associated with lower QoL after one year

6. Vignau and Brunelle (1998); Lille, France	Longitudinal, follow-up after 3 and 6 months	Opiate-dependent subjects treated with buprenorphine (*n* = 69) Comparison between individuals who were prescribed buprenorphine by a general practitioner (*n* = 32) and a treatment agency (*n* = 37)	Tableau d'Évaluation Assistée de la Qualité de Vie (TEAQV)	All patients regained a satisfactory QoL, comparable to the time before their heroin use Significant improvements in 'family relationships', 'occupational status' and 'physical fitness' No significant differences between both subsamples
7. Fischer et al. (2000); Vienna, Austria	Cross-sectional	Pregnant substance-dependent women on opiate maintenance treatment (*n* = 43) Comparison between women on methadone (*n* = 15), slow-release morphine (*n* = 14) and buprenorphine (*n* = 14)	Lancashire QoL profile	No between-group differences 90.7% (very) satisfied with their QoL at time of delivery These women had very negative scores for 'financial situation', but very positive scores for 'partner relationship'
8. Giacomuzzi et al. (2001); Innsbruck, Austria	Cross-sectional	Heroin-dependent subjects (*n* = 61) Comparison of heroin-dependent subjects who entered methadone treatment (*n* = 31) and persons who started MMT 4 months ago (*n* = 30)	Lancashire QoL profile	Persons who were no longer in MMT were significantly less satisfied with their general health and mental health
9. Habrat et al. (2002);Warsaw, Poland	Longitudinal, follow-up after 6 and 12 months	Opiate-dependent subjects entering a methadone program (*n* = 61)	SF-36	HRQoL was extremely low before admission to the methadone program Significant improvements on 7 of the 8 domains during first 6 months; decrease of HRQoL during next 6 months, but not back to the prior level
10. Rooney et al. (2002); Dublin, Ireland	Cross-sectional	Opiate-dependent subjects in treatment (*n* = 72) Comparison of persons in a methadone maintenance program (*n* = 36) and a harm minimisation program (*n* = 36)	SF-36	No between-group differences on any domain of the SF-36 MMT group scored significantly better on 'perceived change in health status' as compared with persons in a harm minimisation programme
11. Dunaj and Kovác (2003); Bratislava, Slovak Republic	Cross-sectional	Convicted male drug addicts who previously used heroin on a regular basis (*n* = 43) Comparison with an unspecified male control group (*n* = 44)	WHOQoL Bref ComQol-A5	Significantly worse scores on subjective measures of QoL for heroin users as compared with control group Only small differences on objective measures between both groups

12. Giacomuzzi et al. (2003); Innsbruck, Austria	Longitudinal, follow-up after 2 and 6 months	Opiate-dependent subjects entering maintenance treatment (*n* = 67) Comparison between methadone (*n* = 38) and buprenorphine (*n* = 29) maintenance treatment	Lancashire QoL profile	Significant improvements in QoL among both groups after 6 months No significant between-group differences
13. Deering et al. (2004); Christchurch, New Zealand	Cross-sectional	Opiate-dependent subjects receiving methadone maintenance treatment (*n* = 107) Comparison with norms for the general population of New Zealand	SF-36	Opiate-dependent individuals scored significantly worse on all 8 domains of the SF-36 44% rated their HRQoL as fair or poor Negative impact of frequency of benzodiazepine and cannabis use on HRQoL
14. Fassino et al. (2004); Torino, Italy	Cross-sectional	Heroin abusers in residential treatment (*n* = 170) Comparison of subjects with (*n* = 115) and without personality disorders (*n* = 55); and with a non-clinical comparison group (*n* = 63)	McGill QoL Questionnaire (MQOL)	Heroin abusers scored significantly worse than control group on all 4 QoL domains and for physical well-being and global QoL Subjects with personality disorders did significantly worse on all 4 domains and for physical well-being and global QoL than those without personality disorders
15. Millson et al. (2004); Toronto, Canada	Cross-sectional	Opiate users entering a low-threshold methadone treatment (*n* = 143) Comparison with US population norms and populations with other chronic diseases	SF-36	Opiate users had significantly worse scores on all 8 domains of the SF-36 as compared with the US general population HRQoL of opiate users was significantly lower than HRQoL of subjects with minor and major medical illnesses Scores were most comparable with those of subjects with psychiatric problems
16. Puigdollers et al. (2004); Barcelona, Spain	Cross-sectional	Opiate-dependent subjects at first entry to methadone maintenance treatment (*n* = 586)	Nottingham health profile (NHP)	44% reported that their general health was poor Worst scores on the domains 'emotional reactions' and 'sleep', best scores for 'pain' and 'physical mobility' Worse HRQoL was related with poly-drug use, low educational level and HIV-positive status
17. Bizzarri et al. (2005); Bolzano, Italy	Cross-sectional	Opiate-dependent individuals in treatment (*n* = 98) Comparison of subjects with (*n* = 41) and without (*n* = 57) psychiatric axis-I disorder Comparison with a non-clinical control group (*n* = 45)	WHOQoL Bref	Opiate-dependent subjects scored significantly worse on 'physical', 'psychological' and 'social' domain than control group Persons with an axis-I disorder had significantly lower scores on the physical and psychological domain than those without such a disorder The three groups did not differ on the domain 'environmental resources'

18. Giacomuzzi, Riemer, et al. (2005); Innsbruck, Austria	Cross-sectional	Opiate-dependent subjects entering maintenance program (*n* = 103) Comparison between men (*n* = 65) and women (*n* = 38)	Lancashire QoL profile	Gender differences were limited Men had significantly better scores on the domains 'law and security', 'mental health' and 'self-esteem'
19. Giacomuzzi, Ertl, et al. (2005); Innsbruck, Austria	Longitudinal, follow-up after 6 and 36 months	Opiate-dependent subjects entering maintenance treatment (*n* = 53) Comparison of persons in methadone (*n* = 24) and buprenorphine (*n* = 29) maintenance treatment	Lancashire QoL profile	'Overall satisfaction' significantly higher after 6 months among the buprenorphine group Buprenorphine group had significantly better scores after 36 months concerning 'leisure time', 'housing', 'law and security' and 'overall satisfaction' Between-group differences disappeared after analyses of covariance The buprenorphine treatment completers had significantly better scores after 6 months on 'job' and 'family' than the non-completers QoL scores were less favourable after 36 months than after 6 months, except significant improvements concerning 'law and security' among the buprenorphine group
20. Haug et al. (2005); California, USA	Cross-sectional	HIV-positive methadone maintenance patients (*n* = 78) Comparison of men (*n* = 42) and women (*n* = 36)	SF-36	Women reported significantly lower scores for 'physical functioning' and 'role emotional'
21. Lofwall et al. (2005); Baltimore, USA	Cross-sectional	Opiate-dependent subjects receiving maintenance treatment (*n* = 67) Comparison of older (*n* = 41) and younger (*n* = 26) persons in the sample; additional comparison with US population norms	SF-36	Compared with the general population, older opiate-dependent subjects scored significantly lower on all 8 domains and younger subjects on 5 HRQoL domains Older opiate-dependent subjects had significantly worse scores for 'physical functioning', 'role limitations physical' and 'bodily pain' than younger opiate-dependent subjects
22. Giacomuzzi et al. (2006); Innsbruck, Austria	Cross-sectional	Opiate-dependent subjects at admission (*n* = 120) Comparison of these treatment seekers with individuals who have been in maintenance treatment for 6 months with slow-release oral morphine (*n* = 40), methadone (*n* = 40) or sublingual buprenorphine (*n* = 40)	Lancashire QoL profile	Least favourable QoL scores for subjects receiving SROM maintenance treatment The methadone and buprenorphine group had better QoL scores than clients at admission No significant differences between methadone and buprenorphine group, except for 'job satisfaction' (in favour of methadone group)

23. March et al. (2006); Andalusia, Spain	Longitudinal, follow-up after 3, 6 and 9 months	Long-term opiate-dependent subjects entering substitution treatment (*n* = 62) Comparison of treatment with diacetylmorphine and oral methadone (*n* = 31) and with oral methadone alone (*n* = 31)	SF-12	Improvements in QoL among both groups after 9 months, but no between-group differences The methadone group improved significantly on mental health, while the diacetylmorphine group improved significantly concerning physical health
24. Millson et al. (2006); Toronto, Canada	Cross-sectional	Opiate users entering low-threshold methadone treatment (*n* = 145)	SF-36	Opiate users had low HRQoL scores at entry HRQoL affected by various factors, including age, emotional and sexual abuse, . . .
25. O'Brien et al. (2006); Sydney, Australia	Cross-sectional and longitudinal analyses, 3-month follow-up	Heroin-dependent subjects (*n* = 326) entering three types of substitution treatment: naltrexone (*n* = 210), methadone (*n* = 70) and buprenorphine (*n* = 46) Comparison with individuals with other chronic medical illnesses treated with maintenance medication; additional comparison with Australian population norms	SF-36	Heroin-dependent subjects had significantly worse 'physical' and 'mental' component scores and lower scores on all 8 domains of the SF-36 than general population Maintenance treatment for heroin users led to comparable or even greater improvements than maintenance treatment for other chronic illnesses All 3 treatment groups had improved significantly on all 8 domains after 3 months, but no between-group differences; their physical health was comparable with the population norms, but mental health was still below the population norms
26. Senbanjo et al. (2006); London, UK	Cross-sectional	Opiate-dependent subjects on methadone treatment (*n* = 192) Comparison of persons with (*n* = 57) and without excessive alcohol consumption (*n* = 135)	SF-12	Negative impact of excessive drinking on HRQoL, especially on 'role functioning'
27. Villeneuve et al. (2006); Toronto, Canada	Longitudinal, 6-month follow-up	Opiate-dependent subjects entering low-threshold methadone treatment (*n* = 183)	SF-36	Significant improvements on 6 domains of the SF-36 and the mental composite score after 6 months 30% recovered on the following domains: 'physical functioning', 'bodily pain', 'vitality', 'mental health', and the 'physical' and 'mental' composite score Biggest improvements in mental health
28. De Jong et al. (2007); Nijmegen, The Netherlands	Longitudinal, follow-up after 1, 10 and 16 months	Detoxified methadone patients starting naltrexone treatment in combination with Community Reinforcement	SF-36 EuroQoL-5D	Significant improvements concerning HRQoL and general health perception over time Abstinent individuals had significantly better scores for HRQoL and

		Approach (*n* = 272)		general health perception after 16 months than non-abstinent persons
29. Hser (2007); Los Angeles, USA	Cross-sectional	Heroin-dependent subjects in and out of treatment (*n* = 242) Comparison of recovered (five years of abstinence) (*n* = 104) and non-recovered (*n* = 138) persons	SF-36	Recovered individuals had better scores on all 8 domains of the SF-36; these differences were significant for 'emotional well-being', 'bodily pain' and 'general health'
30. Padaiga et al. (2007); Kaunas, Lithuania	Longitudinal, follow-up after 3 and 6 months	Opiate-dependent persons involved for the first time in methadone maintenance treatment (*n* = 102)	WHOQoL Bref	Significant improvements on 'physical', 'psychological' and 'environmental' domain of WHOQoL after 6 months, but not on the 'social' domain
31. Maremmani et al. (2007); Pisa, Italy	Longitudinal, follow-up after 9 months	Opiate-dependent persons in methadone maintenance treatment for 3 months (*n* = 213) Comparison of methadone (*n* = 107) and buprenorphine (*n* = 106) group	Quality of life questionnaire	Both groups showed good QoL after 3 months of treatment The buprenorphine group scored in general better after 3 months of treatment and their scores were significantly better for 'total QoL' and 'work' compared with the methadone group QoL of both treatment groups had improved significantly after 9 months
32. Ponizovsky and Grinshpoon (2007); Jerusalem, Israel	Longitudinal, follow-up after 1, 4 and 8 months	Heroin-dependent subjects entering maintenance treatment (*n* = 304) Comparison of methadone (*n* = 45) and buprenorphine (*n* = 259) group	Quality of life enjoyment and satisfaction questionnaire (Q-LES-Q)	Significant improvements among both groups on all domains after 4 and 8 months, including an earlier start of these changes (after 1 month) in the methadone group
33. Rosen et al. (2007); Pennsylvania, USA	Cross-sectional	Methadone patients older than 50 years (*n* = 140) Comparison with US population norms	SF-12	These methadone patients had significantly worse scores on all 8 domains of the SF-36 compared with the general population 57.7% rated their physical health as fair or poor
34. Astals et al. (2008); Barcelona, Spain	Cross-sectional	Opiate-dependent subjects on methadone maintenance treatment (*n* = 189) Comparison of persons with (*n* = 83) and without co-occurring psychiatric disorders (*n* = 106); additional comparison with European population norms	SF-12	Opiate-dependent persons had significantly worse 'physical' and 'mental' component scores compared with the general population No differences were found between persons with and without a dual diagnosis

35. Karow et al. (2008); Hamburg, Germany	Cross-sectional	Long-term opiate-dependent subjects in various types of treatment (*n* = 107)	SF-36	Two years after the start of treatment a negative association was found between HRQoL and personality disorders, family and partner conflicts and the need for treatment Patients who had been in treatment the last year reported a significantly lower HRQoL HRQoL was lowest among the group that had been in psychiatric treatment No significant impact of drug use on HRQoL
36. Lawrinson et al. (2008); WHO study in China, Indonesia, Thailand, Iran, Australia,Lithuania, Poland and Ukraine	Longitudinal, follow-up after 3 and 6 months	Opiate-dependent subjects in developing countries entering substitution treatment (*n* = 726)	WHOQoL Bref	Overall improvement in QoL during study period
37. Luty and Arokiadass (2008); Essex, UK	Cross-sectional	Opiate-dependent subjects receiving substitution treatment (*n* = 105) Comparison with UK population norms	Satisfaction with life scale (SWLS)	Opiate-dependent individuals had a significantly worse overall QoL compared with the general population
38. Winklbaur et al. (2008); Vienna, Austria	Longitudinal, follow-up after 7 and 14 weeks	Opiate-dependent subjects receiving maintenance treatment Comparison of methadone (*n* = 32) and slow-release morphine (*n* = 32) group	Lancashire QoL profile	SROM group had improved significantly after 7 weeks concerning ‘general well-being’, ‘leisure at home’ and ‘mental health’; the methadone group made only significant improvements for ‘general well-being’, but no significant between-group differences No additional significant improvements between weeks 7 and 14 Both groups had significantly better scores after 14 weeks for the domains ‘general well-being’, ‘general state of health’, ‘mental health’ and leisure time’

3.3.3 Substitution treatment and QoL

Sixteen longitudinal studies reported on the medium and long-term effects of substitution treatment on HRQoL and subjective QoL of opiate-dependent subjects. At treatment entry, individuals usually reported poor HRQoL, including emotional problems and difficulties sleeping (Puigdollers et al., 2004). During treatment, Villeneuve et al. (2006) reported significant improvements on six domains of the SF-36 and the 'mental component summary score'. This indicated that most improvements were observed in the 'mental health' domain six months after the start of methadone treatment. Long-term effectiveness of naltrexone maintenance in combination with Community Reinforcement Approach (CRA) has been highlighted in a study by De Jong et al. (2007). As compared with individuals who are treated with maintenance medication for other chronic illnesses (e.g. diabetic patients, schizophrenia . . .), heroin-dependent individuals showed comparable or even greater improvements in HRQoL after substitution treatment (O'Brien et al., 2006). Only the 'mental composite score' improved more among persons on pharmacotherapy for depression.

Comparable positive effects of substitution treatment on subjective QoL were found in various studies. A study in Geneva (Dazord, Mino, Page, & Broers, 1998) showed low scores for subjective QoL at the start of treatment, but reported significant improvements for individuals who were still in MMT after 12 months, including improved satisfaction for the domains related to 'health', 'worries', 'material conditions' and 'money'.

Similar positive results after six months were found in a study among opiate-dependent individuals who engaged in outpatient methadone treatment for the first time (Padaiga, Subata, &Vanagas, 2007). Also, Vignau and Brunelle (1998) compared the subjective QoL of persons treated with buprenorphine by a general practitioner or specialised addiction centre and found similar positive outcomes during substitution treatment for both groups after three months and continuing after six months. In addition, Giacomuzzi et al. (2001) have demonstrated the positive effects of substitution treatment by showing that opiate-dependent individuals scored significantly worse on 'general health' and 'psychological wellbeing' prior to treatment than a similar group of opiate users four months after starting methadone treatment.

Overall, opiate users usually report low HRQoL and subjective QoL at admission to substitution treatment (Millson et al., 2006; Habrat, Chmielewska, Baran-Furga, Keszycka, & Taracha, 2002; Dazord et al., 1998), which is often followed by significant improvements in various life domains during the first months of treatment (Torrens et al., 1997; Reno & Aiken, 1993). Subsequent stabilisation (Lawrinson et al., 2008; Torrens et al., 1997) or regression – not to

the prior level – may follow as treatment continues (Giacomuzzi, Ertl, et al., 2005; Habrat et al., 2002). There may be a negative relationship between individuals' initial expectations about life and QoL after 12 months (Dazord et al., 1998): when faced with difficulties in fulfilling their – often high – expectations, this may have an adverse impact on (HR)QoL (Habrat et al., 2002).

3.3.4 Comparison of various forms of substitution therapy

Nine – three cross-sectional and six longitudinal – studies have compared the effectiveness of two or more types of substitution treatment on individuals' HRQoL or subjective QoL. Methadone treatment was included in all studies.

Buprenorphine

Only one study by O'Brien and colleagues (2006) compared the HRQoL of heroin users who engaged in three different treatment types – naltrexone, methadone and buprenorphine – and found significant improvements after three months on all eight domains of the SF-36 and the 'mental' and 'physical composite score'. The latter scores even approached the general population norms. No significant between-group differences were found for the 'physical' and 'mental composite scores' at follow-up.

The other five studies reported on the subjective QoL of opiate-dependent subjects on buprenorphine treatment. A longitudinal study by Ponizovsky and Grinshpoon (2007) has illustrated that both methadone and buprenorphine maintenance treatment had positive effects on the satisfaction with QoL on all measured domains after four and eight months. Among the methadone group, these improvements were already noticeable after one month of treatment, while it usually takes longer to experience similar positive effects of buprenorphine treatment. On the other hand, Maremmani, Pani, Pacini, and Perugi (2007) reported significantly better subjective QoL scores for total QoL and 'working' at the end of the third month of treatment for the buprenorphine group as compared with the methadone group. By the twelfth month, there was a significant improvement in subjective QoL for both treatment groups, but no significant group differences were shown. Also, Giacomuzzi, Ertl, et al. (2005) compared the subjective QoL between individuals in methadone and buprenorphine maintenance treatment. After six months, both groups showed improvements in QoL, including, for the buprenorphine group, significantly better scores for overall satisfaction with life. Comparable positive results on subjective QoL were found for methadone treatment and treatment with buprenorphine (Ponizovsky & Grinshpoon, 2007; Giacomuzzi et al., 2003,

2006), suggesting that buprenorphine could be as effective as methadone to improve individuals' subjective QoL in the treatment of opiate dependence.

Slow-release oral morphine

Two of the three randomised controlled trials focused on the effectiveness of slow-release oral morphine (Winklbaur et al., 2008; Giacomuzzi et al., 2006). Winklbaur et al. (2008) found similar subjective QoL outcomes between clients who received methadone and those who received slow-release oral morphine (SROM), including significant improvements among both groups after seven weeks. On the other hand, Giacomuzzi et al. (2006) made a comparison of the subjective QoL of individuals at admission to a maintenance programme and persons already in SROM, buprenorphine and methadone treatment; this showed less favourable results among the SROM group as compared with persons at admission and those in methadone and buprenorphine treatment. However, Fischer, Eder, Peternell, and Windhaber (2000) did not find any group differences for these three types of substitution treatment, but this study consisted of a limited number of respondents (n = 43). Although all three studies used the Lancashire QoL profile to measure subjective QoL, the impact of SROM on subjective QoL remains unclear and might be lower than in methadone or buprenorphine treatment. No studies on the HRQoL of opiate-dependent individuals receiving slow-release oral morphine could be retrieved.

Other types of substitution treatment

A randomised controlled trial that compared the HRQoL of opiate-dependent persons who were treated with diacetylmorphine and oral methadone with that of individuals treated only with oral methadone showed that both groups had a better HRQoL after nine months, but no group differences between baseline and the nine-month follow-up could be found (March et al., 2006). A comparison between a methadone maintenance and harm minimisation programme (i.e. needle exchange, daily dose of 20mg methadone and access to medical services) did not reveal group differences for any of the eight domains of the SF-36, although the perceived change in a person's health status as compared with the previous year deteriorated in the harm minimisation programme and improved in the methadone maintenance programme (Rooney, Freyne, Kelly, & O'Connor, 2002). No studies on subjective QoL of other types of substitution treatment could be found.

It should be noted that studies using HRQoL instruments found no differences between various types of substitution treatment, while studies using subjective

QoL instruments reported some differences. It appears that QoL is better than HRQoL at measuring difference between types of treatment.

3.3.5 Mediators and predictors of QoL

Several studies have assessed mediators and predictors of poor (HR)QoL. Most frequently, gender, age, drug use severity and comorbid psychiatric problems have been identified as potential mediating variables. Few studies have included these variables in a multivariate analysis.

Age and gender

An inverse relationship between age and (HR)QoL has been observed: older opiate users usually having worse (HR)QoL than younger users (Millson et al., 2006; Lofwall, Brooner, Bigelow, Kindbom, & Strain, 2005; Bizzarri et al., 2005; Deering et al., 2004), although other authors could not demonstrate such an association (Astals et al., 2008; Puigdollers et al., 2004; Dazord et al., 1998).
With regard to gender, conflicting results were observed. There was a tendency towards lower (HR)QoL scores among opiate-dependent women; this also appears from gender differences in the population norms of the SF-36 (Hopman et al., 2000). These differences are most obvious at admission (Haug et al., 2005; Puigdollers et al., 2004; Ryan&White, 1996), although Bizzarri et al. (2005) also reported significantly lower QoL scores in the 'physical' and 'psychological' domain for women in treatment. On the other hand, several authors (Millson et al., 2006; Deering et al., 2004; Habrat et al., 2002; Dazord et al., 1998) did not observe a significant association between gender and (HR)QoL. Moreover, none of the multivariate analyses could demonstrate an independent impact of gender on (HR)QoL (Astals et al., 2008; Torrens et al., 1997).

Drug and alcohol use

No clear relationship was found between (HR)QoL and use of specific substances nor the amount, duration and frequency of drug use (Deering et al., 2004; Millson et al., 2006; Ryan & White, 1996). Almost all studies that have reported a (negative) association between drug use and QoL used an HRQoL instrument. Consequently, little information was available on the impact of drug use on other life domains (e.g. family relations, leisure time, social participation, housing). A study by Bizzarri et al. (2005) – the only study using a multidimensional QoL instrument – found no significant influence of current substance use on any of the QoL domains measured by the WHOQOL Bref. Similar results were found concerning HRQoL in a study by Karow, Verthein,

Krausz, and Schäfer (2008), who found no association between actual drug use and HRQoL two years after start of treatment. Moreover, in at least one study, the use of cannabis and alcohol were likely to have a positive effect on various domains of HRQoL (Ryan &White, 1996).
Recent cocaine use (last 30 days) has been associated with worse scores on the 'mental component' of the SF-36 (Millson et al., 2006). Astals et al. (2008) found inconsistent results for the influence of cocaine use and frequency of use in the last 30 days on the 'physical component score', while intravenous cocaine use correlated significantly with lower mental health scores. Also, regular use of stimulant drugs (Astals et al., 2008) correlated negatively with the 'physical component' score of the SF-36, while older age at first injection was associated with worse 'physical component' scores (Millson et al., 2006). Moreover, a negative impact of excessive alcohol use on HRQoL, in particular on 'role limitations', 'social functioning' and 'physical health', has been shown by several authors (Karow et al., 2008; Senbanjo, Wolff, & Marshall, 2006; Ryan & White, 1996).
Worse overall HRQoL scores among heroin users 12 months after starting MMT have been associated with use of higher amounts of heroin at baseline and with the prescription of higher methadone doses, while side use of heroin did not predict worse HRQoL (Torrens et al., 1997). On the other hand, Deering et al. (2004) found no association with methadone dosage, nor could they demonstrate an association between subjective QoL and the number of MMT admissions and duration of current treatment, respectively.
A 33-year follow-up study by Hser (2007) compared recovered (at least five years of heroin abstinence) with non-recovered heroin-dependent males and found better HRQoL scores among the recovered individuals. Karow et al. (2008) found lower HRQoL scores among opiate-dependent persons who were still in MMT after two years than in the group no longer in treatment. Also Eklund, Melin, Hiltunen, and Borg (1994) have reported more favourable subjective QoL scores for clients who successfully terminated MMT as compared with clients who were still in treatment.

Comorbidity

A limited number of studies have reported on the influence of psychiatric disorders on (HR)QoL of opiate-dependent individuals. According to Astals et al. (2008), no direct influence of dual diagnosis could be observed on the 'physical' and 'mental composite score' of heroin abusers during residential treatment, as both groups reported a very poor HRQoL. On the other hand, other authors (Karow et al., 2008; Fassino et al., 2004) have demonstrated the negative impact of having a personality disorder on the subjective QoL and HRQoL of

opiate users. In addition, opiate-dependent persons with an axis-1 disorder reported significantly lower scores for the 'psychological' and 'physical domain' of the WHOQoL Bref as compared with persons without a psychiatric disorder (Bizzarri et al., 2005).

Other mediators and predictors of QoL

Occasionally, some other variables have been linked with a poor (HR)QoL, such as recent utilisation of medical services (Ryan & White, 1996), prescription of medication (Deering et al., 2004), having a chronic disorder, recent hospitalisation for physical problems, and emotional and sexual abuse (Millson et al., 2006). Legal problems (Karow et al., 2008) and imprisonment (Astals et al., 2008) have been associated with a poor 'physical health', while family conflicts (especially with partner) have been linked with both lower 'mental' and 'physical health' component scores (Karow et al., 2008). Inconsistent results have been found for the influence of educational level on HRQoL (Astals et al., 2008; Deering et al., 2004; Puigdollers et al., 2004). Only a few studies have looked at the role of HIV on the (HR)QoL of opiate-dependent individuals and these also lead to conflicting findings (Puigdollers et al., 2004; Habrat et al., 2002; Dazord et al., 1998; Torrens et al., 1997).

3.4 Discussion

3.4.1 Opiate dependence and QoL

Based on this review of 38 articles, the subjective QoL and HRQoL of opiate-dependent individuals is relatively low as compared with the general population and people with various medical illnesses. One possible explanation may be that (HR)QoL is often assessed among opiate users starting treatment, which may result in an underestimation of (HR)QoL among the wider population of opiate users (Buchholz, Krol, Rist, Nieuwkerk, & Schippers, 2008). Moreover, drug users in treatment differ from untreated drug users in various ways (e.g. higher rates of depressive disorders) (Ross, Lin, & Cunningham, 1999; Eland-Goossensen, van de Goor, & Garretsen, 1997; Rounsaville & Kleber, 1985). Opiate users report lower scores on mental health in particular, while their physical well-being is less affected. O'Brien et al. (2006) even found comparable results with the general population concerning physical health after a three-month treatment period. The low scores for mental health among opiate-dependent individuals and the even lower (HR)QoL scores for opiate users with comorbid psychiatric disorders stress the need for treatment services (e.g.

substitution treatment) that address psychiatric and psychological problems. Coordination of care including integrated mental health and drug treatment – both starting from a harm reduction perspective – would be an essential element of such programmes (Drake, Mueser, & Brunette, 2007).

Generally, participation in substitution treatment seemed to have a positive effect on individuals' (HR)QoL. Improvements on various life domains – including HRQoL and subjective QoL – were most obvious during the first months of treatment. This may be explained by the fact that opiate-dependent individuals often find themselves in a crisis situation at the start of treatment and enter treatment in very poor condition, resulting in very low (HR)QoL scores at admission (Reno & Aiken, 1993; Hser, 1988). Still, the observed improvements persisted over a long-term period – although less favourable than during the first months of treatment – illustrating the positive influence of substitution treatment on (HR)QoL. Other factors (e.g. specific characteristics of the group that completed treatment) may contribute to these positive results. Some variables (e.g. age, gender, drug and alcohol use, comorbidity) may mediate individuals' (HR)QoL, illustrating the multiple influencing factors. Given the negative association between age and (HR)QoL (Lofwall et al., 2005), greater attention should be given to the QoL of older drug users in opiate treatment (Gfroerer, Penne, Pemberton, & Folsom, 2003). Although results were often conflicting, a number of studies have reported lower (HR)QoL scores among women. Also, the influence of drug use on (HR)QoL remains unclear, and this is reflected in inconsistent findings. Nevertheless, a negative impact of excessive alcohol use on HRQoL was shown in various studies (Karow et al., 2008; Senbanjo et al., 2006; Ryan & White, 1996).

Other aspects in life (e.g. emotional, social, physical status) probably have a bigger impact on (HR)QoL than current drug use, which necessitates looking beyond abstinence-oriented treatment goals. Moreover, most studies that have reported on potential determinants of (HR)QoL were correlational, but further research is needed to investigate the direction of this association in multivariate analyses.

Various substitution treatments are now available (e.g. methadone, buprenorphine, slow-release morphine, diacetylmorphine), but further research is necessary to explore which populations benefit most from which type of substitution treatment. All nine studies selected for this review compared methadone – the gold standard for substitution treatment (Ward et al., 1999) – with another product. Few substance-specific differences have been found concerning individuals' HRQoL, suggesting that these treatment types contribute equally to people's health status. When applying a broader subjective perspective on QoL, slightly more favourable results were observed among the buprenorphine group (Maremmani et al., 2007; Giacomuzzi, Ertl, et al., 2005).

The less intense withdrawal of buprenorphine, as a partial agonist (Bickel et al., 1988), and the fact that there is no need for daily administration (Marsch, Bickel, Badger, & Jacobs, 2005), might have a positive influence on long-term subjective QoL. Further research is necessary to explore the differential effectiveness of substitution treatment, in which a broad view to QoL is applied rather than one that is limited to HRQoL.

3.4.2 Why should QoL have a prominent role in addiction research?

The chronic nature of drug use problems makes it necessary to look at outcomes of drug treatment from a broad perspective based on clients' needs and focusing on continuity of care rather than on acute interventions (O'Brien & McLellan, 1996). Most outcome studies have been oriented towards recovery and termination of use rather than on a continuing care perspective (Vanderplasschen et al., 2004; McLellan, 2002). However, Stark and Campbell (1991) have shown that one of the most important reasons given by methadone clients for following treatment was to improve their satisfaction with life. Drug use is not always the reason why people seek treatment, but rather problems in other life domains (legal, social) (Gerstein & Harwood, 1990; Rounsaville & Kleber, 1985). Moreover, few studies have found a direct link between the use of illegal drugs and poor QoL. Measuring QoL can broaden our view and provide new insights – beyond the direct consequences of drug dependence – about aspects of life that really matter to clients, apart from their physical and mental health state. Drug users do not primarily associate QoL with health, but rather with social inclusion and self-determination (De Maeyer, Vanderplasschen, & Broekaert, 2009). Studies measuring HRQoL are using the wrong construct if their focus is QoL (Cummins et al., 2004). The reductionistic perspective of HRQoL lacks attention to the complexity of drug users' lives, limiting it to health-related issues; instead, other aspects that have a great impact on the subjective well-being of individuals (e.g. self-esteem, life goals, social participation) also need to be incorporated. This does not imply that HRQoL is not a useful concept – it offers interesting information on effects of treatment on someone's health status – but it does not provide a broader view of the quality of life with its focus on the absence of pathology (Cummins et al., 2004). Consequently, it will be necessary to start from a holistic paradigm when talking about QoL, giving attention to the individual as a whole in interaction with his or her environment (Laudet, Becker, & White, 2009; Brown, Renwick, & Nagler, 1996).

The concept of QoL has gradually become an important outcome measure in health research (Katschnig, 2006), but the application of this concept in clinical practice is still limited (Frost et al., 2007). Although QoL has become a popular

clinical term to demonstrate the multidimensional approach of treatment based on clients' needs, in reality, the concept often turns into idle talk. Assessing the QoL of drug users in practice is both feasible and useful and can offer additional diagnostic information – providing a total picture of the client – to tailor clinical practice better to clients' needs (Laudet et al., 2009).

3.4.3 Methodological issues and challenges for future research

Although this paper has several strengths, a number of limitations should be noted. First, a statistical meta-analysis was impossible due to the variety of instruments and outcome measures. Moreover, only three studies used a randomised controlled design (Winklbaur et al., 2008; Giacomuzzi et al., 2006; March et al., 2006) and further such studies that incorporate QoL as an outcome measure are needed (Miller &Wilbourne, 2002).

This is the first study that provides a systematic review of published research of QoL among opiate users. Comparisons of subjective QoL were limited, due to the small number of studies applying this approach and the use of different instruments. Also there was only one study which assessed QoL over a longer-term period of three years (Giacomuzzi, Ertl, et al., 2005).

Second, some important conceptual and methodological issues related to the current research on QoL may hamper the interpretation of findings. In addiction research, HRQoL has often been used as a synonym of QoL (Zubaran & Foresti, 2009). However, it is necessary to make a distinction between these terms, because they measure two different concepts (Smith et al., 1999). Various studies in this review used an HRQoL-instrument to measure the concept QoL, resulting in misuse of both concepts. Health is almost always seen as an essential component or at least a subdomain of QoL, but it does not embrace the concept as a whole (Laudet et al., 2009; Raeburn & Rootman, 1996). Health status cannot be equated with QoL. Therefore, caution is needed when studies are compared using both terms – HRQoL and QoL – to talk about the same 'concept' (Connor, Saunders, & Feeney, 2006). It is important to be attentive to this conceptual confusion when interpreting study results. In this review a clear distinction was made between articles measuring HRQoL or the broader concept QoL. Researchers should clarify explicitly what they mean when they use the concept 'QoL'. They need to determine in advance what concept they want to measure and choose an appropriate instrument to assess this specific concept. 'Having no physical or psychological limitations' is not the same as having a high QoL; HRQoL does not give information on clients' own experiences about the goodness of life, and the application of an HRQoL instrument is unsuitable to measure QoL. It can even be questioned whether 'QoL' should be included in the term HRQoL, or whether a more health-related term such as 'functional

status' or 'health status' would be more appropriate (Moons, Budts, & De Geest, 2006).

Third, various instruments are used to measure (HR)QoL, thus inhibiting generalisations. Generic as well as specific instruments are applied to measure the (HR)QoL of drug users, but the use of generic instruments prevails (Zubaran & Foresti, 2009). In general, generic instruments are less responsive to detecting treatment effects (Wiebe, Guyatt, Weaver, Matijevic, & Sidwell, 2003), while specific instruments provide information relevant to a particular group, resulting in different primary accents. The fact that the majority of studies used a generic instrument might result in limited useful outcomes on the specific situation of drug users. None of the selected studies used a (HR)QoL instrument, specifically targeted at drug users. This may be because there are few scales available to measure the QoL of substance users (Vanagas et al., 2004). To our knowledge, the injection drug user quality of life scale (IDUQOL) (Brogly, Mercier, Bruneau, Palepu, & Franco, 2003) is the only validated QoL instrument. No studies using the IDUQOL were included in this review, since the instrument has only been applied to IDUs and no results have been reported on opiate-dependent IDUs in particular. Various studies that have used the same instrument (e.g. SF-36) are still difficult to compare as they have reported results on different parts of the questionnaire: some studies report on the eight different domains of the SF-36, other just mention the mental and physical composite score, and a limited number of studies use both the domain and composite scores. Some authors (Rooney et al., 2002; Falck, Wang, Siegal, & Carlson, 2000) have even questioned whether the SF-36 is an appropriate instrument to assess drug users' HRQoL, given the potential misinterpretation of some questions and since it might miss the connection with drug users' personal perception of QoL.

Finally, the importance individuals ascribe to various domains is a factor often lacking in QoL research. Only one study (Dazord et al., 1998) – using the subjective quality of life profile – reported on the importance of domains from drug users' perspectives. It would be useful to learn more about the important issues for the individual whose QoL is assessed, leading to a more emancipatory approach in addiction treatment and research. Given the importance of subjective perceptions in QoL, it is further remarkable that no qualitative studies were included in this review. Qualitative research could provide more in-depth information on the factors that influence drug users QoL (Robinson, 2006; Neale, Allen, & Coombes, 2005). It will further be important to involve drug users in this research, starting from their personal perspectives on a concept like QoL (De Maeyer et al., 2009).

3.4.4 Conclusion

This review highlights the need for further research on QoL among drug users. It is often included in studies as a side issue, but research with a primary focus on QoL is limited and should be expanded to include a broad focus on all components of life that are related to the goodness of life. Starting from this perspective, it is recommended that a subjective, multidimensional QoL profile is applied rather than a one-dimensional approach. An increase in the uniformity of the instruments used to measure QoL would improve the comparability of the findings across studies and could influence decision making in a positive way. Furthermore, it will be important to integrate QoL in clinical practice, so the use of the concept QoL will go beyond the boundaries of the research field.

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Chapter 4

Current quality of life and its determinants among opiate-dependent individuals five years after starting methadone treatment[3]

[3] Based on De Maeyer, J., Vanderplasschen, W., Lammertyn, J., van Nieuwenhuizen, C., Sabbe, B., & Broekaert, E. (in press). Current quality of life and its determinants among opiate-dependent individuals five years after starting methadone treatment. *Quality of Life Research*, doi: 10.1007/s11136-010-9732-3.

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Abstract

Objective: This study explores the current QoL of opiate-dependent individuals who started outpatient methadone treatment at least five years ago and assesses the influence of demographic, psychosocial, drug and health-related variables on individuals' QoL.

Methods: Participants (n = 159) were interviewed about their current QoL, psychological distress and severity of drug-related problems, using the Lancashire Quality of Life Profile, the Brief Symptom Inventory and the Addiction Severity Index. Potential determinants of QoL were assessed in a multiple linear regression analysis.

Results: Five years after the start of methadone treatment, opiate-dependent individuals report low QoL scores on various domains. No association was found between drug-related variables and QoL, but a significant negative impact of psychological distress was identified. Severity of psychological distress, taking medication for psychological problems and the inability to change one's living situation were associated with lower QoL. Having at least one good friend and a structured daily activity had a significant, positive impact on QoL.

Conclusion: Opiate-dependent individuals' QoL is mainly determined by their psychological well-being and a number of psychosocial variables. These findings highlight the importance of a holistic approach to treatment and support in methadone maintenance treatment, which goes beyond fixing the negative physical consequences of opiate dependence.

4.1 Introduction

Estimations of the prevalence of opiate use in the European Union range from 1 to 6 per thousand inhabitants (EMCDDA, 2009). Although this number is considerably lower when compared with the prevalence of cocaine, cannabis and other illicit drug use, dependence rates are much higher among opiate users (EMCDDA, 2008). Opiates, heroin in particular, remain the primary drug for which individuals seek treatment and the vast majority of drug-related infectious diseases and mortality is associated with opiate use (EMCDDA, 2009). Methadone substitution treatment is the standard, evidence-based treatment for opiate dependence in most countries (Amato et al., 2005), but recently buprenorphine has been introduced as an alternative substitute drug to reduce heroin use and related health and social problems.

Given the chronic, relapsing nature of drug problems and the various life domains they affect (Vanderplasschen, Rapp, Wolf & Broekaert, 2004; McLellan, Lewis, O'Brien & Kleber, 2000), the attention for quality of life (QoL) in the field of drug abuse research has grown rapidly (Zubaran & Foresti, 2009). The majority of these studies have assessed drug users' health-related quality of life (HRQoL) (Preau et al., 2007; Senbanjo, Wolff & Marshall, 2006; Villeneuve et al., 2006), especially among opiate-dependent individuals in treatment (Zubaran & Foresti, 2009). Evidence is available that the HRQoL of opiate-dependent individuals is low in comparison with the general population and individuals suffering from other chronic diseases and most comparable with that of individuals with psychiatric problems (Millson et al., 2004; Ryan & White, 1996). In general, opiate-dependent individuals report poor mental health scores, while their scores for physical functioning are usually considerably higher (De Maeyer, Vanderplasschen & Broekaert, 2010). HRQoL is a concept frequently misused as a synonym for QoL (Cummins, Lau & Stokes, 2004; Muldoon, Barger, Flory & Manuck, 1998). It primarily focuses on the effects of a disease on individuals' daily functioning (Wiklund, 2004), with special attention for their physical and mental health (Mooney, 2006; Millson et al., 2004).

The comprehensive concept of QoL has a more positive connotation and focuses on persons' overall well-being and satisfaction with life (Laudet, Becker & White, 2009). Such a holistic approach to QoL with attention for drug users' own experiences and expectations is often lacking in drug abuse research. Up till now, the focus in most studies is exclusively on the absence of pathology and individuals' functional status (HRQoL). However, it is necessary to make a distinction between HRQoL and QoL, since individuals' health status may have an impact on QoL, but does not represent it (Smith, Avis & Assmann, 1999).

Health is included as an important domain in most QoL definitions (Muldoon et al., 1998), but when individuals are asked to define important domains of QoL health is seldom mentioned as a primary domain (De Maeyer, Vanderplasschen & Broekaert, 2009; Anderson & Burckhardt, 1999). A qualitative study concerning drug users' perspectives on the concept QoL demonstrated that social inclusion and self-determination are regarded as central components of QoL (De Maeyer et al., 2009). On the other hand, some quantitative studies have identified health-related issues as determinants of QoL (Bizzarri et al., 2005; Schaar & Öjehagen, 2003; Smith & Larson, 2003), illustrating the possible influence of health status on the concept QoL.

A limited number of studies have reported lower QoL scores for opiate-dependent individuals when compared with the general population or a non-clinical control group (Luty & Arokiadass, 2008; Bizzarri et al., 2005; Fassino, Abbate Daga, Delsedime, Rogna & Boggio, 2004). Only recently QoL has become an outcome measure in research on the effectiveness of (various forms of) substitution treatment (Winklbaur, Jagsch, Ebner, Thau & Fischer, 2008; Maremmani, Pani, Pacini & Perugi, 2007; Padaiga, Subata & Vanagas, 2007; Amato et al., 2005). In general, opiate-dependent individuals report low QoL and HRQoL scores at admission to substitution treatment (De Maeyer et al., 2010). Participation in substitution treatment brings about positive effects on individuals' HRQoL and QoL, especially during the first months of treatment (Padaiga et al., 2007; March, Oviedo-Joekes, Perea-Milla, Carrasco & the PEPSA team, 2006; O'Brien et al., 2006; Villeneuve et al., 2006; Habrat, Chmielewska, Baran-Furga, Keszycka & Taracha, 2002; Giacomuzzi et al., 2001; Torrens et al., 1997). However, a stabilization of these improvements or even less favorable outcomes can be noticed from a long-term perspective (Giacomuzzi, Ertl, Kemmler, Riemer & Vigl, 2005; Habrat et al., 2002).

A better understanding of determinants that are associated with high QoL scores may advice treatment services and policymakers how they can improve individuals' QoL (Carr, Gibson & Robinson, 2001). Studies that provide information on predictors of QoL among opiate-dependent persons are limited and have mainly focused on HRQoL. Moreover, these studies have not resulted in unequivocal findings. An inverse relationship between age and HRQoL has been shown in various studies (Millson et al., 2006; Lofwall, Brooner, Bigelow, Kindbom & Strain, 2005; Deering et al., 2004), while inconsistent findings have been reported regarding the role of gender (Haug et al., 2006; Millson et al., 2006; Deering et al., 2004; Habrat et al., 2002; Ryan & White, 1996). The impact of severity of dependence on HRQoL remains unclear (Astals et al., 2008; Karow, Verthein, Krausz & Schäfer, 2008; Millson et al., 2006; Puigdollers et al., 2004; Ryan & White, 1996), but the negative impact of

excessive alcohol use on HRQoL has been demonstrated in several studies (Karow et al., 2008; Costenbader, Zule & Coomes, 2007; Senbanjo et al., 2006). Emotional and psychiatric problems (e.g. depression, personality disorders) appear to have a detrimental impact on individuals' HRQoL (Batki, Canfield, Smyth & Ploutz-Snyder, 2009; Carpentier et al., 2009; Millson et al., 2006). Social support may have a positive influence on HRQoL (Preau et al., 2007), but conflicts with family and partner have been associated with lower HRQoL scores (Karow et al., 2008). As demonstrated by Millson and colleagues (2006), who identified more than a dozen different determinants of the mental and physical composite scores of the SF-36, opiate-dependent individuals' HRQOL is affected by multiple factors.

Besides the limited number of studies on determinants of QoL, few authors have controlled for the influence of potential covariates in a multivariate design. Consequently, results are often limited to bivariate analyses of correlates of QoL (Becker, Curry & Yang, 2009; Giacomuzzi et al., 2005; Fassino et al., 2004). Despite the specific treatment needs of opiate users, only one study by Bizzarri and colleagues (Bizzarri et al., 2005) examined the independent impact of dual diagnosis, gender, age and current substance use on QoL of opiate-dependent individuals, using the WHOQOL-BREF. This study demonstrated a significant impact of dual diagnosis on all four QoL domains, a negative association of older age and female gender with some domains, while current substance use had no significant impact on QoL. Also, Conroy and colleagues (2008) found no association between QoL and drug-using practices (e.g. drug use, sharing of needle equipment) among injecting drug users, but a range of psychosocial factors (e.g. family support, having friends) influenced their current QoL. According to another study, the overall QoL of substance users in treatment was negatively associated with older age, specific medical conditions (i.e., arthritis, ulcers), severity of drug use, being treated in a detoxification unit and recent hospitalization for mental health problems (Smith & Larson, 2003). Finally, improvement of psychiatric symptoms was demonstrated to be the best predictor of increased QoL among severely mentally ill substance abusers (Schaar & Öjehagen, 2003).

Given the dearth of research on predictors of QoL among opiate-dependent individuals and given the assumption that substitution treatment contributes to the stabilization of opiate users' living situation, the aim of this article is to study the current QoL of persons who started outpatient methadone treatment at least five years ago. Furthermore, the influence of recent heroin use and psychological distress on current QoL is assessed, as well as the question which demographic, psychosocial, drug and health-related variables are independent predictors of a better QoL.

4.2 Methods

4.2.1 Subjects and data collection

This study was set up as a cross-sectional study of the current QoL of a cohort of opiate-dependent individuals who started outpatient methadone treatment between 1997 and 2002 in the region of Ghent (Belgium). This time frame was chosen, since the first medical-social care center for outpatient methadone treatment (MSOC) was opened in 1997 and since we intended to monitor the current situation of opiate-dependent persons who started methadone treatment at least five years ago. No central methadone register was available from the beginning, but it has been estimated that during this period (1997-2002) between 1,000 and 1,500 persons have been involved in methadone treatment in this region (Colpaert, Vanderplasschen & Broekaert, 2007; Vanderplasschen, Colpaert, Lievens & Broekaert, 2003).

Inclusion criteria for the study were being over 18 years, a diagnosis of opiate dependence at the start of methadone treatment and having started this treatment in the region of Ghent between January 1997 and December 2002. Participants were recruited by the use of various media (e.g. flyers, advertisements in newspapers, interviews on local television and radio), through snowball sampling and by staff members of methadone programs for the group still in treatment. In addition, the regional network of drug treatment agencies informed eligible drug users about the study. Individuals were excluded from the study if the interview could not be administered in Dutch (n = 2), if methadone treatment was started after 2002 (n = 10) or outside the region of Ghent (n = 13) or when they just received methadone as part of residential detoxification (n = 5).

In total, 159 subjects participated in this non-randomized study. Forty-one participants (25.8%) were no longer in methadone treatment by the time of the interview, while almost three-quarters of the sample (74.2%) was currently still on methadone. The mean duration of methadone treatment was 7.6 years (SD = 4.4). A high proportion of the sample (86.5%) followed at least two methadone treatment episodes, which is not surprising given the high drop-out rates in substitution treatment (Haskew, Wolff, Dunn & Bearn, 2008).

Interviews took place between March 2008 and August 2009 and lasted between 45 and 120 min. Individuals received 20€ for participation in the study. A written informed consent was obtained from all participants before the start of the study. Participation was entirely voluntary and confidentiality was assured. Data were collected during face-to-face interviews in a setting of the participants' choice (e.g. at the methadone clinic, in the person's house, in a public place, in a residential treatment center). Interviews focused on respondents' current QoL

and on lifetime and current severity of substance use and related problems. The study was approved by the ethical committee of the Faculty of Psychology and Educational Sciences of the Ghent University, in accordance with internationally accepted criteria for research (2006/51).

4.2.2 Instruments

The Lancashire quality of life profile

In order to measure individuals' current QoL, we made use of the modified Dutch version of the Lancashire Quality of Life Profile, an instrument commonly used in mental health research (van Nieuwenhuizen, Schene, Koeter & Huxley, 2001; van Nieuwenhuizen, Schene, Boevink & Wolf, 1998). The LQOLP has been used in a number of studies among opiate-dependent individuals to measure effects of substitution treatment on QoL (Winklbaur et al., 2008; Giacomuzzi et al., 2006, 2005, 2003, 2001; Fischer, Eder, Peternell & Windhaber, 2000). The LQOLP measures individuals' satisfaction with various QoL domains and their global well-being. The Dutch version of the LQOLP consists of ten subscales: 'health', 'leisure and social participation', 'living situation', 'family relations', 'finances', 'safety', 'positive self-esteem', 'negative self-esteem' (measured by a modified version of the Self-Esteem Scale; (Rosenberg, 1965)), 'framework' and 'fulfilment'. Perceived QoL or individuals' subjective ratings are assessed on a 7-point Likert scale (from '1. Life cannot be worse' to '7. Life cannot be better') for all domains, except the domains 'positive self-esteem', 'negative self-esteem', 'framework' and 'fulfilment'. The latter are measured on a 3-point Likert scale, but were afterward recoded on a 7-point Likert scale. Low QoL has been defined as 'a score below 4' (van Nieuwenhuizen & Nijman, 2009). Besides these specific QoL domains, global well-being is assessed by means of Cantril's ladder (Cantril, 1965), a happiness scale (Gurin, Veroff & Feld, 1960) and an average life satisfaction score ('how satisfied are you with your life as a whole?'). The LQOLP also contains objective items on various life domains (e.g. occupation, housing situation, psychological problems) (Ruggeri, Warner, Bisoffi & Fontecedro, 2001). Internal consistency, reliability and validity of the LQOLP have been demonstrated to be satisfactory (van Nieuwenhuizen et al., 2001, 1998; Oliver, Huxley, Priebe & Kaiser, 1997). For the purpose of this study, we make use of the 10 domain scores, the average life satisfaction score (to measure global well-being) and a total QoL score, a sum score based on the ten specific QoL domain scores (Schneider, Wooff, Carpenter, Brandon & McNiven, 2002).

The EuropASI

In order to measure the severity of substance use and related problems, we used the EuropASI, an adapted and validated version of the Addiction Severity Index (ASI) for the European context (Kokkevi & Hartgers, 1995; McLellan et al., 1992). The EuropASI is a semi-structured clinical interview, including an assessment on seven areas of functioning: medical status, employment/support, alcohol use, drug use, legal problems, family/social relationships and psychological problems (McLellan, Luborsky, Woody & O'Brien, 1980). An ASI composite score is calculated for each domain (range 0-1), with higher scores indicating higher problem severity (Koeter & Hartgers, 1996). In this study, only the domains 'medical status', 'alcohol', 'drugs' and 'legal status' were assessed, since 'family', 'employment' and 'psychological problems' were extensively explored as part of the objective items of the LQOLP. It is a valid approach to assess ASI domains separately.

Brief symptom inventory

The Dutch version of the Brief Symptom Inventory (BSI), a short version of the widely applied SCL-90, was used to measure psychological distress. This is a validated, multi-dimensional self-report questionnaire, consisting of 53 items (De Beurs, 2006). Psychometric properties of the BSI have been demonstrated to be sufficient (De Beurs, 2006; Derogatis & Melisaratos, 1983). The instrument measures recent psychological complaints (past 7 days) on 9 subscales: 'somatization', 'obsessive-compulsive', 'interpersonal sensitivity', 'depression', 'anxiety', 'hostility', 'phobic anxiety', 'paranoid ideation', and 'psychoticism'. Symptoms are rated on a 5-point Likert scale ranging from '0. Not at all' to '4. Extremely', with higher scores indicating severe complaints (De Beurs, 2006). A Global Severity Index (GSI), an average rating of all 53 items (range 0-4), is calculated as an overall score of psychological functioning. Clinical cut-off scores for psychological distress are available for all 9 subscales and the GSI. The cut-off score of the GSI (0.70) is used as a general measure of psychopathology (De Beurs, 2006; Derogatis & Melisaratos, 1983). Besides the GSI, the positive symptom distress index (PSDI) measures the intensity of symptoms, while the positive symptom total (PST) represents the number of items indicating psychological distress.

4.2.3 Statistical analyses

The characteristics of the sample were assessed using descriptive statistics. Domain-based QoL scores and a global well-being score were calculated. A profile was determined, including the number of respondents with low QoL on each domain and low global well-being. Independent samples *t*-tests were used to compare domain scores and global well-being between subjects who recently used heroin and those who did not do so. In addition, respondents who scored higher than the clinical cut-off score for overall psychopathology were compared with those with a GSI below 0.70. A Bonferroni correction was applied to address the problem of multiple comparisons and to protect against type 1 errors in the bivariate analyses. To investigate the independent contribution of individual predictors to QoL, a multiple linear regression model was built using a stepwise search procedure including forward selection as well as backward elimination. The dependent variable (total QoL) was compiled as a sum score of the ten specific domain-based QoL scores. The 28 predictors initially included in the stepwise search were selected based on associations found in previous research and based on existing theories and conceptualizations of QoL (Katschnig, 2006; Rapley, 2003; Schalock, 1996). The following predictors were entered: gender, age, educational level, employment, having debts, inability to change living situation in the past year, having an intimate relationship, having at least one good friend, having a structured form of daily activities, having been convicted of a crime in the past year, inability to have more contact with own family in the past year, age at first heroin use, age at first methadone use, years of regular heroin use, years of regular methadone use, injecting behavior, number of days in outpatient drug or alcohol treatment during the last 30 days, currently in methadone treatment, number of methadone treatments, taking medication for psychological problems, ever been hospitalized for psychological problems, been a victim of violence in the past year, having chronic medical complaints, ASI drug composite score, ASI alcohol composite score, ASI composite score for medical status, ASI composite score for legal status and the Global Severity Index of the BSI. We acknowledge that the sample size (n = 159) is relatively small to test this large number of predictors. Therefore, we used resampling techniques (bootstrapping) which confirmed the validity of the final model. The final model is presented in the 'Results' section. All model assumptions were satisfied and no significant multicollinearity was present between the predictors in the final model. All statistics were done using SPSS 15.0. The statistical significance level was set at $\alpha = 0.05$.

4.3 Results

4.3.1 Study sample characteristics

Study participants were predominantly male (74.8%), with an average age of 36.6 years (SD = 7.5) (see **Table 4.1**). 56.6% did not complete any form of secondary education. About one quarter of the participants (26.4%) currently had a paid job. The largest group of subjects had never been married (69.8%) and lived alone (40.3%). The mean age of onset of regular heroin use was 21.4 years (SD = 5.6), and they had been consuming heroin regularly for, on average, 10.8 years (SD = 6.7). About half of the participants (49.7%) reported recent heroin use. The mean age of onset of regular methadone use was 26.0 years (SD = 6.4). On average, they had been taking methadone during 7.6 years (SD = 4.4). Of the sample, 54.1% scored above the clinical cut-off score for overall psychopathology, while 87.9% of the sample scored above the clinical cut-off score for psychological distress for at least one subscale of the BSI. 'Paranoid ideation' (65.6%) was the most frequently reported psychological complaint within the clinical range, followed by 'somatization' (56.7%) and 'psychoticism' (55.4%).

4.3.2 Current quality of life

Individuals who had started outpatient methadone treatment between five and ten years ago appeared most satisfied at the moment with the domains 'framework', 'positive self-esteem' and 'safety' (see **Table 4.2**). The domain 'framework', which relates to having meaningful perspectives in life, had the highest average satisfaction score. Respondents were least satisfied with their 'finances' and 'family relations'.

While the mean scores provide an overall picture for the total sample, **Fig. 4.1** shows the number of individuals reporting a low QoL (score < 4) on the various domains. The results are divergent between the domains, with in particular a large number of subjects with a low QoL score for 'finances' (68.6%) and 'family relations' (44.9%). Also, more than 30% of the participants had a low QoL concerning 'living situation' (34.0%), 'negative self-esteem' (32.1%) and 'fulfilment' (31.4%). Low satisfaction with fulfilment means that those subjects do not feel able to fulfil their life goals or have difficulties realizing their life goals. In comparison with the other domains, relatively few subjects (24%) reported low QoL concerning health issues. Overall, 31.4% of the respondents appear to be dissatisfied with their current global well-being.

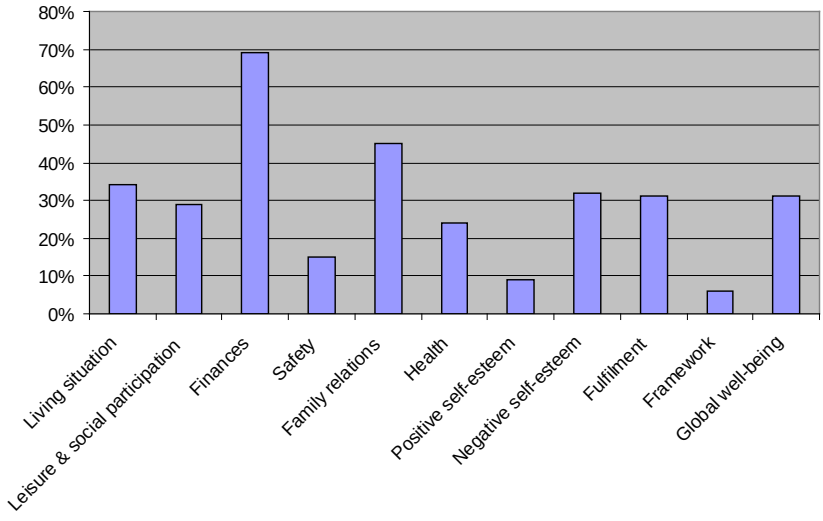
Table 4.1: Sociodemographic and drug use-related characteristics of opiate-dependent individuals who started methadone treatment between 1997 and 2002 (*n* = 159)

Characteristics	Sample
Age [(*M SD*)]	36.6 (7.5)
Male (%)	74.8
Marital status (%)	
Unmarried	69.8
Married	7.5
Divorced/widowed	22.6
Intimate relationship (%)	45.3
One or more children (%)	50.9
Paid job (%)	26.4
Age at first use [(*M SD*)]	
Heroin	21.4 (5.6)
Methadone	26.0 (6.4)
Years of regular use [(*M SD*)]	
Heroin	10.8 (6.7)
Methadone	7.6 (4.4)
Injecting behavior (%)	
Ever	81.8
In the last 30 days	27.8
Substance use in the last 30 days (%)	
Alcohol	61.0
Cannabis	59.2
Benzodiazepines	57.2
Heroin	49.7
Cocaine	31.4
Average duration of methadone (%)	
< 3 months	11.8
3-6 months	6.5
> 6 months	10.5
> 12 months	71.2
Average dose of methadone (%)	
1-39mg	39.5
40-59mg	24.3
60-109mg	28.9
> 109mg	7.2
Consulted a doctor for psychological problems during the last year (%)	45.3
Taken medication for psychological problems during the last year (%)	58.5
Psychological complaints [(*M SD*)]	
Somatization	.89 (.81)
Obsessive-compulsive	1.14 (.88)
Interpersonal sensitivity	1.11 (1.02)
Depression	1.12 (.97)
Anxiety	1.04 (.90)
Hostility	.80 (.82)
Phobic anxiety	.58 (.68)
Paranoid ideation	1.13 (.85)
Psychoticism	.78 (.74)
Overall psychopathology	.98 (.70)

Table 4.2: Mean scores (range 1-7) for the 10 domains and global well-being of the LQOLP for individuals who started methadone treatment between 1997 and 2002 (*n* = 159)

Life domain	Mean	SD
Framework	6.05	1.0
Positive self-esteem	5.96	1.3
Safety	5.23	1.0
Fulfilment	4.69	1.1
Negative self-esteem	4.68	1.5
Health	4.54	.95
Leisure and social participation	4.41	.95
Living situation	4.34	1.4
Family relations	3.94	1.7
Finances	3.31	1.4
Global well-being	4.04	1.5

Fig. 4.1: Proportion of respondents reporting low QoL for each specific domain and global well-being (N = 159)



4.3.3 Impact of current heroin use and psychological distress on QoL

The sample was split up into two subgroups, based on the presence or absence of recent heroin use (last 30 days). Only the domain score for 'finances' was significantly lower among recent heroin users ($t(157) = 2.998$, $p = .003$), while current heroin use did not affect other QoL domains.

Table 4.3: Comparison of the mean scores for the 10 domains and global well-being of the LQOLP between individuals who recently used heroin and those who did not (*n* = 159)

Life domain	No heroin use *n* = 80 [(M SD)]	Heroin use *n* = 79 [(M, SD)]	*t(df)*	*P*
Framework	6.2 (1.0)	5.9 (1.0)	1.67(157)	.096
Positive self-esteem	6.0 (1.3)	5.9 (1.3)	.32(157)	.749
Safety	5.3 (1.0)	5.2 (1.1)	.52(157)	.605
Fulfilment	4.8 (1.1)	4.5 (1.1)	1.72(157)	.088
Negative self-esteem	4.8 (1.5)	4.6 (1.5)	1.00(157)	.317
Health	4.6 (0.9)	4.5 (1.0)	.15(157)	.882
Leisure and social participation	4.5 (0.9)	4.3 (1.0)	1.65(157)	.100
Living situation	4.4 (1.4)	4.3 (1.5)	.16(157)	.874
Family relations	4.1 (1.6)	3.7 (1.8)	1.38(157)	.168
Finances*	3.6 (1.4)	3.0 (1.2)	3.00(157)	.003*
Global well-being	4.2 (1.6)	3.8 (1.4)	1.71(157)	.089

* Significant at the Bonferroni-corrected $P < 0.005$ level

A comparison of the respondents who scored higher than the clinical cut-off score for overall psychopathology (≥0.70) with those who did not score within the clinical range showed a strong negative impact of current psychological distress on QoL. The former group had significantly lower scores on all QoL domains and for global well-being.

Table 4.4: Comparison of the mean scores for the 10 domains and global well-being of the LQOLP between persons with an overall psychopathology of ≥ 0.70 score and persons with a lower score (*n* = 157)

Life domain	No psychopathology *n* = 72 [(M SD)]	Psychopathology *n* = 85 [(M, SD)]	*t(df)*	*P*
Framework	6.3 (0.8)	5.8 (1.1)	3.09(152.96)	.002*
Positive self-esteem	6.6 (0.8)	5.5 (1.4)	6.17(133.66)	.000*
Safety	5.5 (0.9)	5.0 (1.1)	3.16(153.06)	.002*
Fulfilment	5.2 (1.0)	4.2 (1.0)	5.70(155)	.000*
Negative self-esteem	5.5 (1.4)	4.0 (1.2)	7.08(155)	.000*
Health	5.0 (0.8)	4.2 (0.9)	6.07(155)	.000*
Leisure and social participation	4.7 (0.7)	4.2 (1.0)	3.98(147.86)	.000*
Living situation	4.8 (1.2)	4.0 (1.5)	3.60(154.47)	.000*
Family relations	4.4 (1.6)	3.6 (1.7)	3.02(155)	.003*
Finances*	3.7 (1.3)	3.0 (1.3)	3.17(155)	.002*
Global well-being	4.5 (1.4)	3.7 (1.5)	3.36(155)	.001*

* Significant at the Bonferroni-corrected *P* < 0.005 level

4.3.4 Determinants of QoL

In order to determine which factors influenced total QoL, a multiple linear regression analysis was conducted. The final model obtained through stepwise regression is presented in **Table 4.5**. It contains five predictor variables, jointly explaining 60% of the variance of the total QoL score. Higher scores for psychological distress, inability to change one's living situation and taking medication for psychological complaints were significantly associated with lower QoL. On the other hand, having at least one good friend and having a structured daily activity significantly predicted a higher QoL score. The strongest negative predictor of total QoL was the total score for psychological distress, while having at least one good friend was the predictor with the strongest positive impact on total QoL.

Table 4.5: Final model of the linear multivariate regression analysis including significant predictors of total QoL

Remaining predictors	*B*	SE	Beta	*t*	*P*
(Constant)	5.420	.138		39.36	.000
Psychological distress	-.573	.060	-.539	-9.50	.000
Inability to change living situation	-.441	.093	-.252	-4.75	.000
Medication for psychological complaints	-.300	.083	-.197	-3.62	.000
Good friend	.309	.089	.184	3.48	.001
Structured daily activities	.228	.087	.147	2.62	.010

R^2 = .616
Adjusted R^2 = .602
P < .05

4.4 Discussion

This study revealed low QoL scores on various domains among opiate-dependent individuals five to ten years after they had started outpatient methadone treatment. Although no general population norms are available with which these results can be compared, a significantly higher proportion of the study sample reported low QoL on six of the ten LQOLP domains in comparison with hospitalized male psychiatric patients (van Nieuwenhuizen & Nijman, 2009). This finding can be partly explained by the high prevalence of psychological complaints in the study sample. Various studies have demonstrated high psychiatric co-morbidity in opiate-dependent individuals (in methadone treatment) (Carpentier et al., 2009; Rodríguez-Llera et al., 2006; Cacciola, Alterman, Rutherford, McKay & Mulvaney, 2001; Callaly, Trauer, Munro & Whelan, 2001). Previous studies on QoL of opiate-dependent individuals have reported lower QoL scores among persons with co-occurring psychiatric problems when compared with individuals without psychiatric co-morbidity (De Maeyer et al., 2010). Similar findings can be observed in studies among persons with severe mental illnesses, in which a negative effect of substance abuse on QoL has been demonstrated (Urbanoski, Cairney, Adlaf & Rush, 2007; Lam & Rosenheck, 2000). It appears that individuals with a so-called dual diagnosis are more vulnerable for having a poor QoL. Given the high prevalence of psychological symptoms in opiate-dependent individuals, it can be questioned whether it would not be more appropriate to develop integrated mental health and substance abuse services as the standard of care (Drake, Mueser & Brunette, 2007).

Persons who started methadone treatment more than five years ago are generally dissatisfied with their ‘finances’. This has also been observed in other studies

that have used the LQOLP to assess the effectiveness of opiate substitution treatment (Giacomuzzi et al., 2006, 2005, 2003, 2001; Fischer et al., 2000). The dissatisfaction with their financial situation may not be surprising, given the high cost of supporting a drug consumption habit (Information services, 2007) and drug users' substantial debts. Individuals' poor education and unemployment may further affect their social and economic situation (Carpentier et al., 2009; Vanderplasschen, De Bourdeaudhui & Van Oost, 2002; Meulenbeek, 2000). Yet, the domain 'finances' also appears to be the domain with the lowest satisfaction among the general population (Evans & Huxley, 2002).

The high mean score on the domain 'framework' shows that opiate-dependent individuals have a sense of purpose with their life and future plans that give them satisfaction. Life meaning important to buffer stress, which in its turn has a positive influence on QoL (Laudet, Morgan & White, 2006). Studies by Moomal (1999) and Zika and Chamberlain (1992) have demonstrated a clear association between life meaning and psychological well-being. Life meaning is a domain that needs more attention in QoL measurements, given the high importance that is attributed to this domain by persons with drug and mental health problems (De Maeyer et al., 2009; van Nieuwenhuizen et al., 1998). The high proportion of subjects who report a low QoL on the domain 'fulfilment' indicates that many opiate-dependent individuals think it will be very difficult to actually realize their desired life goals. Experiences of stigma (Murphy & Irwin, 1992) and discrimination (Young, Stuber, Ahern & Galea, 2005) often hinder drug users in their daily functioning and are associated with poor mental and physical health (Ahern, Stuber & Galea, 2007).

Low scores on one QoL domain do not necessarily imply low scores on another domain, illustrating the necessity to assess QoL from a multidimensional perspective. The relatively high scores on the domain 'health' demonstrate the appropriateness of methadone programs for reducing health problems, but – in combination with the previous observation – also stress the need for looking beyond health-related aspects. Generally, measuring QoL should be given a more prominent role in the assessment and monitoring of drug problems, starting from individuals' needs and expectations in order to postulate and adjust treatment goals (Kolind, Vanderplasschen & De Maeyer, 2009).

To our knowledge, this is the first study applying a multivariate design to assess the independent impact of various demographic, psychosocial, drug- and health-related determinants on QoL among opiate-dependent individuals who started methadone treatment at least five years ago. This study confirms the findings of Conroy (2008) and Bizzarri (2005), who found no association between drug-related variables and the QoL of injecting drug users. Neither the ASI composite scores for drugs and alcohol, nor other drug-related variables, nor current

treatment status were significant determinants of QoL. Also, in a validation study of the IDUQOL (Hubley, Russell & Palepu, 2005), very low and non-significant correlations were observed between several drug-related variables and overall QoL. Bivariate comparisons of study subjects who recently used heroin and persons who did not do so, only showed a significantly lower mean QoL score for the domain 'finances' among current heroin users. These findings illustrate the limited influence of severity of drug use problems on current QoL and highlight the need for treatment goals other than stopping or reducing drug use. Being abstinent from drugs or reduced drug problem severity is not necessarily accompanied by improvements in QoL, since giving up the positive aspects associated with drug use (e.g. prestige/status in the drug scene) and coping with various stressors (e.g. loneliness, boredom, discrimination) may have a negative impact on individuals' QoL (De Maeyer et al., 2009).

Psychological distress appears to have the strongest negative impact on current QoL. As much as 25% of the variance of total QoL was independently explained by the severity of psychological distress. Also, taking medication for psychological complaints has a strong negative impact on QoL. Both determinants demonstrate the strong negative impact of psychological problems on the current QoL of opiate-dependent individuals. Consequently, early identification of psychological problems based on systematic assessment procedures and attention for the issue of co-morbidity during the treatment process is a prerequisite in methadone treatment.

Contextual factors, such as having a good friend and a structured daily activity, had a significant positive influence on the total QoL of opiate-dependent individuals. The protective role of social support on drug consumption (Garmendia, Alvarado, Montenegro & Pino, 2008; Mizuno, Purcell, Dawson-Rose, Parsons & Team The S.U.D.I.S., 2003) and retention in treatment (Dobkin, De Civita, Paraherakis & Gill, 2002) has been shown in various studies. The observation that social networks have a positive impact on opiate-dependent persons' QoL stresses the need for establishing individuals' (non-professional) social networks during and after methadone treatment in order to enhance their social inclusion. This is further illustrated by the positive impact of having daily activities on total QoL: not necessarily employment, but having a meaningful plan for the day showed a positive association with total QoL. Meaningful day activities and social support are both generic determinants of QoL and have also been identified as protective factors for QoL among the general population and specific subpopulations (e.g. persons with depressive disorders, disabilities) (Chung, Pan & Hsiung, 2009; Diener & Ryan, 2009; Ay-Woan, Sarah, LyInn, Tsyr-Jang & Ping-Chuan, 2006; Schalock & Verdugo Alonso, 2002; Viemerö & Krause, 1998). The inability to change one's living situation during the past year further had a significant negative impact on persons' total QoL. The importance

of stable housing for individuals' QoL has been recognized in various studies on QoL of dually diagnosed individuals (Conroy et al., 2008; Bebout, Drake, Xie, McHugo & Harris, 1997). These independent correlates of QoL illustrate the need to assist opiate users in methadone treatment with housing and occupational issues. The influence of elements other than health-related factors (e.g. having an occupation, a good friend) on QoL cannot be underestimated. Due to a unilateral focus on health, caregivers may only have a partial picture of clients' quality of life and the various factors influencing it (Anderson & Burckhardt, 1999). Furthermore, improving one's QoL (Laudet et al., 2009; Stark & Campbell, 1991) and tackling non-health-related problems (e.g. family relations, legal status, employment status) have been identified as the main reasons for going into treatment (Deering et al., 2004).

Ultimately, this study has revealed that opiate-dependent individuals still need support on various life domains five to ten years after starting methadone treatment and that a satisfactory QoL is in particular mediated by psychological well-being and some psychosocial variables. Consequently, a more holistic approach to methadone maintenance – and drug treatment in general – is recommended, which goes beyond pharmaceutical maintenance and medical care to include specific attention for psychological complaints and support in housing, occupational and social inclusion issues (Carpentier et al., 2009; Millson et al., 2006; Vanagas, Padaiga & Bagdonas, 2006).

4.4.1 Limitations of the study

Some limitations of this study should be taken into account. First, the sample size (n = 159) was relatively small. Findings may therefore not be generalized to other groups of opiate users. Second, respondents were not selected randomly, nor did we apply a controlled design. It is unclear if the sample was fully representative for the group of opiate-dependent individuals starting methadone treatment five to ten years ago (n = 1,500), but the age and gender distribution of the sample was identical to that of persons in outpatient methadone treatment in the region of Ghent between 1997 and 2002 (Vanderplasschen et al., 2003). The representativeness of the sample was enhanced by applying various strategies to recruit study participants (e.g. flyers, media campaign, contacts with drug, health and social services). It would further be interesting to focus in future research on the QoL of other groups of drug users (e.g. cocaine users, opiate users out of treatment) (Rudolf & Watts, 2002) and compare these findings with those reported here. Third, given the cross-sectional design of the study, causality could not be examined. This study only reports associations, because possible determinants and outcomes were measured at the same time. Future longitudinal

research should address issues of directionality and linearity. Fourth, psychological distress was measured by means of a short symptom checklist (BSI). Consequently, the prevalence of psychiatric disorders was not assessed, as no standardized diagnostic instrument was used. Still, validation studies have shown high correlations between BSI subscales and diagnostic instruments measuring the same constructs (De Beurs, 2006). Fifth, 60% of the variance of total QoL was explained by our final regression model, illustrating that other factors (not included in the model) will have had an impact on total QoL. Qualitative in-depth interviews could provide more information on how drug users perceive QoL and on factors that affect the QoL of drug-using individuals (De Maeyer et al., 2009; Neale, Allen & Coombes, 2005). Finally, given the conceptual discrepancy between QoL and HRQoL, researchers need to make explicit what they are measuring exactly. Therefore, it would be interesting to compare both concepts – QoL and HRQoL – in future research, in order to illustrate the different conceptualization of both concepts.

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Chapter 5

Domain-specific determinants of opiate-dependent individuals' quality of life and the indirect effect of current heroin use [4]

[4] Based on De Maeyer, J., Vanderplasschen, W., Lammertyn, J., van Nieuwenhuizen, C., & Broekaert, E. (submitted). Domain-specific determinants of opiate-dependent individuals' quality of life and the indirect effect of current heroin use. Submitted for publication in European Addiction Research.

Abstract

Objective: Studies on determinants of quality of life (QoL) among opiate-dependent individuals are scarce. Moreover, findings concerning the role of severity of drug use are inconsistent. The aim of the present study was to investigate the association between domain-specific QoL and demographic, social, person, health and drug-related variables, and to identify potential indirect effects of current heroin use on opiate-dependent individuals' QoL.

Methods: A cohort of opiate-dependent individuals who started outpatient methadone treatment at least five years previously (n = 159) was interviewed about their current QoL, psychological distress, satisfaction with methadone treatment and the severity of drug-related problems, using the Lancashire Quality of Life Profile, the Brief Symptom Inventory, the Verona Service Satisfaction Scale for Methadone Treatment and the EuropASI. Domain-specific determinants of QoL and potential indirect effects of current heroin use on QoL were examined, using multiple linear regression models and path analyses.

Results: Regression analyses revealed different combinations of determinants (e.g. satisfaction with treatment, fulfilment and medication for psychological complaints) for various domains of QoL. No direct effect of current heroin use on QoL was retained, but path analyses demonstrated its total indirect effects on the domains of 'living situation', 'finances' and 'leisure and social participation'.

Conclusion: None of the QoL domains were defined by the same compilation of determinants, illustrating the particularity of each QoL domain and the need for a multidimensional approach to the concept. The relationship between current heroin use and various domains of opiate-dependent individuals' QoL is complex, indirect and mediated by psychosocial and treatment-related variables.

5.1 Introduction

Quality of Life (QoL) has been acknowledged in various disciplines both as a significant outcome measure of treatment effectiveness and also as an important aspect in assessment of individuals' needs for support (Katschnig, 2006; Schalock et al., 2002). Attention for QoL in substance abuse research, especially among opiate-dependent individuals in treatment, has grown extensively during the last decade (Zubaran & Foresti, 2009). This increasing interest is largely the result of the recognition of opiate (and other forms of substance) dependence as a chronic, relapsing disorder (Van den Brink & Haasen, 2006; Van den Brink, Goppel & van Ree, 2003; McLellan, Lewis, O'Brien & Kleber, 2000) and the tremendous impact of chronic illnesses on the daily life of individuals (Devins et al., 2001). Opiates remain the primary drug for the majority of persons entering drug treatment (EMCDDA, 2008) and opiate dependence is associated with various social and health-related problems such as unemployment, poverty, homelessness and infectious disease (EMCDDA, 2008; Information Services, 2007; Gray & Fraser, 2005; Platt, 1995). In view of the potential negative consequences of a drug using lifestyle on various life domains (McLellan et al., 2000; Best et al., 1998), it is important to measure the QoL of opiate-dependent individuals as a multidimensional concept (De Maeyer, Vanderplasschen & Broekaert, 2009). Domain-specific assessment of QoL provides concrete information about individuals' experiences with life, based on satisfaction with various life domains (e.g. material well-being, safety, intimacy) (Wu & Yao, 2007), making it very useful for clinical practice (Cummins, Lau & Stokes, 2004).

An important aim in QoL research is to acquire knowledge of the determinants that are associated with high QoL scores. A better understanding of these factors can provide evidence about how treatment services and policy makers can improve QoL (Chan & Yeung, 2008; Carr, Gibson & Robinson, 2001; UK700 Group, 1999; Sorensen & Naess, 1996). It can also advance the development of a theoretical model of QoL for opiate-dependent individuals. However, studies on determinants of QoL among drug dependent individuals are scarce and findings concerning the role of, among others, severity of drug use, age and gender are inconsistent (De Maeyer, Vanderplasschen & Broekaert, 2010; Rudolf & Watts, 2002). Moreover, the majority of these studies focus on determinants of overall QoL, without paying attention to variation between QoL domains (Conroy, Kimber, Dolan & Day, 2008; Laudet, Morgan & White, 2006; Smith & Larson, 2003; Schaar & Öjehagen, 2003). And yet a number of studies among mental health populations have demonstrated that various domains of QoL are determined by domain-specific predictors (Trompenaars, Masthoff, Van Heck,

Hodiamont & De Vries, 2005; Ruggeri, Gater, Bisoffi, Barbui & Tansella, 2002; Ritsner et al., 2000). By the sole use of total QoL scores to identify determinants, the association between a specific QoL domain and a certain determinant may disappear, since some associations can counterbalance others. Consequently, it is necessary to gain more insight into the impact of domain-specific determinants of QoL among opiate-dependent individuals. Evidence is available, for example, that psychological problems are associated with lower QoL scores (Smith & Larson, 2003; Lam & Rosenheck, 2000; UK700 Group, 1999), but limited information exists about which specific domains are most affected by these psychological problems.

At the time of writing, only two studies (Ponizovsky et al., 2010; Bizzarri et al., 2005) have provided information on domain-specific determinants of QoL among opiate-dependent persons. One is a recent longitudinal study by Ponizovsky and colleagues (2010), who used the Quality of Life Enjoyment and Satisfaction Questionnaire. This QoL instrument, designed specifically for persons with mental health problems, has only rarely been used in an opiate-dependent population (De Maeyer et al., 2010). In this study, the authors identified eight different predictors (e.g. psychosocial distress, support from friends, self-efficacy) which all explained different, significant amounts of variance in each QoL domain among heroin-dependent individuals who were undergoing buprenorphine maintenance treatment. Limited attention was given to the impact of drug-use-related variables, such as severity of dependence or injecting behaviour on QoL. The second study, by Bizzarri and colleagues (2005), used the widely applied WHOQOL-BREF to clarify the specific impact of dual diagnosis, gender, age and current substance use on four domains (physical, psychological, social and environmental) of QoL among opiate-dependent individuals in treatment. This study demonstrated a significant impact of dual diagnosis on all QoL domains and a negative association between both older age and female gender on three QoL domains, but found no significant impact of current substance use on any QoL-domain (Bizzarri et al., 2005). In this study, however, a generic QoL instrument, without attention to the specific population of opiate-dependent individuals, was used (Vanagas, Padaiga & Subata, 2004). Moreover, only a limited number of independent variables (n = 4) were included and no attention was given to psychosocial aspects (e.g. being in a relationship) which may influence opiate users' QoL.

To address some of the limitations of the studies by Ponizovsky (2010) and Bizzarri (2005), we used a comprehensive and multidimensional measure to assess various domains of QoL. The Lancashire Quality of Life Profile (LQOLP) is a specific QoL-instrument for persons with mental health problems (van Nieuwenhuizen, Schene, Koeter & Huxley, 2001; van Nieuwenhuizen, Schene, Boevink & Wolf, 1998) which has frequently been applied to assess opiate-

dependent individuals' QoL (Luty & Arokiadass, 2008; Giacomuzzi, Kemmler, Ertl & Riemer, 2006; Giacomuzzi et al., 2003; Fischer, Eder, Peternell & Windhaber, 2000). The LQOLP provides objective (e.g. occupation, housing situation, psychological problems) as well as subjective information on various QoL domains. Both the abovementioned studies applied a series of independent multiple regression analyses but did not look at the potential indirect effects of possible determinants of QoL, such as drug use. Such an indirect effect may explain why some studies found a negative effect of severity of drug use on substance users' QoL (Smith & Larson, 2003; Schaar & Öjehagen, 2003), while others failed to do so (Conroy et al., 2008; Bizzarri et al., 2005). In addition, opiate-dependent individuals report significantly worse QoL scores than the general population or non-clinical control groups (Luty & Arokiadass, 2008; Bizzarri et al., 2005; Fassino, Abbate Daga, Delsedime, Rogna & Boggio, 2004), suggesting that heroin use might have a negative impact on QoL. For these reasons, further research is needed to assess the indirect effects on and mediating factors of QoL. The potential indirect effects of substance use on the QoL of opiate-dependent individuals are rarely – if ever – investigated. In this context, the objectives of this study are to (a) determine which factors influence various domains of QoL among opiate-dependent individuals and (b) identify both the direct and indirect effects of current heroin use on different domains of QoL by using path analysis (Kline, 2005). We hypothesize that specific domains of QoL are determined by different variables and that current heroin use has an indirect effect on QoL rather than a direct one.

5.2 Methods

5.2.1 Study sample

This study was set up as a cross-sectional, non-randomized study on the current QoL of a cohort of opiate-dependent individuals who started outpatient methadone treatment in the region of Ghent (Belgium) between 1997 and 2002. This time frame was chosen because the first medical-social care centre for outpatient methadone treatment was opened in 1997 and because we intended to monitor the current situation of opiate-dependent persons who started methadone treatment during the first six years of the centre's activities. It has been estimated that during that period, between 1000 and 1500 persons underwent some form of methadone treatment in the region (Colpaert, Vanderplasschen & Broekaert, 2007; Vanderplasschen, Colpaert, Lievens & Broekaert, 2003). Criteria for inclusion in our sample were an age of at least 18 and opiate dependence at the start of treatment and commencement of treatment in the region of Ghent

between January 1997 and December 2002. Of those individuals originally recruited for the study, some were excluded for not meeting the time-frame criterion (n = 10) or the geographical criterion (n = 13). Individuals were also excluded if the interview could not be administered in the Dutch language (n = 2) or when they had followed exclusively residential methadone treatment (n = 5).

5.2.2 Procedure

Participants were recruited by the use of various media (e.g. flyers, advertisements in newspapers, interviews on local television and radio), through snowball sampling and by staff members of methadone programmes for the group still in treatment. In addition, the regional network of drug treatment agencies informed eligible drug users about the study. Informed written consent was obtained from all participants prior to their inclusion in the study. Participation was entirely voluntary and confidentiality was assured. Individuals received €20 for participation. In total, 159 subjects participated. Data were collected through face-to-face interviews in a setting of the participant's choice (e.g. at the methadone clinic, in the person's home, in a public place, in a residential treatment centre). The interviews took place between March 2008 and August 2009 and lasted between 45 and 120 minutes. They focused on respondents' current QoL, lifetime and current severity of substance use and related problems, psychological complaints in the seven days prior to the interview and satisfaction with treatment. The study was approved by the ethical committee of the Faculty of Psychology and Educational Sciences of Ghent University, in accordance with internationally accepted criteria for research (2006/51).

5.2.3 Measures

Lancashire quality of life profile

In order to measure individuals' current QoL, we used the Dutch version of the Lancashire Quality of Life Profile (van Nieuwenhuizen et al., 2001, 1998), an instrument frequently used in mental health research (Priebe et al., 2010). The LQOLP includes various dimensions of life and global well-being and starts from individuals' self-reported subjective perspectives. It also covers several objective items on each domain. The Dutch version of the LQOLP consists of six subscales: 'health', 'leisure and social participation', 'living situation', 'family relations', 'finances' and 'safety'. Each subscale measures clients' satisfaction

on that domain and is rated on a 7-point Likert scale, ranging from '1. Life cannot be worse' to '7. Life cannot be better'. In addition to the QoL Profile, 'positive self-esteem' and 'negative self-esteem' are measured by means of a modified version of the Self-Esteem Scale (Rosenberg, 1965), while 'meaningful life' is assessed using the Life Regard Index (Debats, Vanderlubbe & Wezeman, 1993), which comprises two subscales 'framework' and 'fulfilment' (measured in our study on a 3-point Likert scale). Internal consistency, reliability and validity of the LQOLP have been demonstrated to be satisfactory (van Nieuwenhuizen et al., 2001, 1998; Oliver, Huxley, Priebe & Kaiser, 1997). In this study, the six domain scores of QoL were treated as dependent variables, while the subscales concerning 'self-esteem' and 'meaningful life', as well as the objective items in the questionnaire, were regarded as possible determinants of the six domains of QoL (Hansson & Bjorkman, 2007).

The EuropASI

The EuropASI, a version of the American Addiction Severity Index (ASI) adapted and validated for the European context, was assessed to measure the severity of substance use and related problems (Kokkevi & Hartgers, 1995; McLellan et al., 1992). The EuropASI is a semi-structured clinical interview, including an assessment on seven areas of functioning: medical status, employment/support, alcohol use, drug use, legal status, family/social relationships and psychological problems. For this study, only the domains 'medical status', 'alcohol', 'drugs' and 'legal status' were measured, since family, employment and psychological problems are explored extensively as part of the objective items of the LQOLP. Assessment of only some ASI domains is valid because severity scores are computed separately for each domain (McLellan, Luborsky, Woody & O'Brien, 1980).

Brief symptom inventory

Current psychiatric distress (during the last week) was assessed using the Dutch version of the Brief Symptom Inventory (BSI). The BSI is a short form of the SCL-90. It is a 53-item validated, multi-dimensional, self-report questionnaire (De Beurs, 2006; Derogatis & Melisaratos, 1983). A Global Severity Index (GSI), the average rating of all 53 items (range 0-4), is calculated as an overall score of psychological functioning, with higher scores indicating more severe psychopathology. Utilizing standard cut-off scores, overall BSI scores are categorized as 'healthy' (BSI<.70) or 'pathological' (BSI≥.70) (De Beurs, 2006). The psychometric properties of the BSI are adequate (De Beurs, 2006; Derogatis & Melisaratos, 1983). A study examining the psychometric properties of the BSI

among substance users has demonstrated the greater usefulness of the Global Severity Index over scores on the sub-dimensions of the BSI, suggesting that GSI is the most suitable indicator of overall psychopathology (Benishek, Hayes, Bieschke & Stoffelmayr, 1998). Consequently, the GSI is used in this study as a possible determinant of QoL.

Verona service satisfaction scale for methadone treatment

In order to measure clients' satisfaction with treatment, we used the Verona Service Satisfaction Scale for methadone treatment (VSSS-MT), a self-report scale specifically developed to assess satisfaction with methadone maintenance treatment (de los Cobos et al., 2002). The VSSS-MT consists of 27 items and is a multidimensional measure which assesses satisfaction with treatment services in the previous three months on four domains: basic interventions, specific interventions, social worker skills and psychologist skills. Satisfaction with services is rated on a 5-point Likert scale, ranging from '1. Terrible' to '5. Excellent', which results in a satisfaction score for each domain and in an overall score for satisfaction with treatment. The psychometric properties of the questionnaire are satisfactory (de los Cobos et al., 2002). The overall satisfaction score with methadone treatment is used in this study as a potential determinant of QoL.

5.2.4 Statistical analyses

The independent contribution of individual variables (e.g. demographic, social, drug related) on different domains of QoL was assessed in a two step process. First, a theory-driven selection resulted in a set of 28 variables (see **Table 5.1**). These were included on the basis of associations found in previous research and on that of existing theories and conceptualizations of QoL (De Maeyer et al., 2010; Katschnig, 2006; Schalock, 1996). Second, to refine this selection, the dependent variables which measure the six QoL domains were regressed on the 28 variables selected in the first step as well as on their two-way interactions. Six multiple linear regression models were built, using a stepwise search procedure including both forward selection and backward elimination. For the categorical variables 'current methadone dose' and 'current treatment period', dummy variables were created and the group not currently in methadone treatment was used as reference category. As the sample size for testing this large number of variables is relatively small, resampling techniques (bootstrapping) were used to obtain a stable set of variables within each of the different models. Stable variables and/or interactions were selected if they occurred in at least 50% of the

bootstrap samples. Fourteen variables were identified as stable explanatory variables of at least one QoL domain (See **Table 5.1**). None of the two-way interactions proved to be stable.

Table 5.1: Selected variables after theory-driven selection (first column) and after data-driven selection (multiple regression analyses) (second column)

Theory driven selection	Data driven selection
Demographic variables	
Age	Age
Gender	
Psychosocial variables	
Employment	Employment
Structured daily activity	Structured daily activity
Intimate relationship	Intimate relationship
Having at least one good friend	
Inability to change living situation in the past year	Inability to change living situation in the past year
Inability to have more contact with family in the past year	
Current juridical situation	
Drug-related variables	
Years of regular heroin use	
Injecting behaviour in the last 6 months	
Recent heroin use (last 30 days)	
Recent cocaine use (last 30 days)	
Recent cannabis use (last 30 days)	
Recent alcohol use (> 5 glasses/day) (last 30 days)	
Treatment-related variables	
Currently in methadone treatment	Currently in methadone treatment
Years of regular methadone use	
Current methadone dose	Current methadone dose
Current treatment period	
Satisfaction with treatment	Satisfaction with treatment
Health-related variables	
Chronic medical complaints	
Physical complaints in the last 30 days	Physical complaints in the last 30 days
Medication for psychological problems	Medication for psychological problems
Overall psychopathology	Overall psychopathology
Person-related variables	
Positive self-esteem	Positive self-esteem
Negative self-esteem	
Fulfilment	Fulfilment
Framework	Framework

Path analysis

To examine potential indirect effects of current heroin use on each of the six QoL domains measured, the variables constituting the six regression models obtained previously, together with current heroin use, were entered in path analyses. Initially, the models were built to examine the direct effect of all the independent variables plus current heroin use on each QoL domain. In addition, we examined whether the stable explanatory variables selected in the previous step mediated the effect of current heroin use on the particular domain of QoL. This was achieved by adding paths between current heroin use and the other independent variables. To develop path models with a good overall fit to the data, a number of adjustments were made, based on the modification indices reported by the software package and/or on theoretical grounds. The initial model for the domain 'leisure and social participation' was adjusted by adding the effect of 'fulfilment' on structured daily activity. Since 'fulfilment' and 'framework' both measure the concept 'life meaning', the latter variable was excluded from this model. In the 'family relations' model, the effect of employment on age and on structured daily activity was added. The path model for 'health' was adapted in the following way: an indicator of physical health was included, namely 'recent physical complaints', and one of the two indicators of mental health, namely the total score for psychopathology, was removed in order to develop a model with a good overall fit. By doing so, both physical and mental components of health were included in the model. Moreover, the effect of 'fulfilment' and of 'recent physical complaints' on 'medication for psychological problems' was added.

The final models are presented in **Fig. 5.1** to **5.6**. Arrows in the path diagrams show the effects examined. The path coefficients represent maximum likelihood estimations of the standardized regression coefficients and provide an indication of the strength of the direct associations between the two variables involved. Goodness-of-fit indices were evaluated by means of the Chi-square test of model fit, the comparative fit index (CFI) and the root mean square error of approximation (RMSEA). A non-significant Chi-square test of model fit, CFI values > 0.9 and RMSEA values < 0.5 are considered as good fit indices (Hu & Bentler, 1999, 1998; Browne & Cudeck, 1993). All descriptive statistics were produced using SPSS 15.0. We used R (version 2.10) for the stepwise regression analyses and bootstrapping. Path analyses were conducted with Mplus 5.23, using maximum likelihood parameter estimation from the sample covariance matrices. The statistical significance level was set at $\alpha = 0.05$.

5.3 Results

5.3.1 Sample characteristics

Table 5.2 presents the characteristics of the study sample. Respondents were predominantly male (74.8%), with an average age of 36.6 years (SD = 7.5). The mean duration of methadone treatment was 7.6 years (SD = 4.4). A high proportion of the sample (86.5%) had followed at least two methadone treatment episodes. Almost three-quarters of the sample (74.2%) was currently still on methadone treatment. Half of the participants (49.7%) reported recent heroin use.

5.3.2 Final path models

None of the six QoL domains was constituted by the same compilation of variables (cf. **Fig. 5.1-5.6**). Satisfaction with methadone treatment, structured daily activity, employment and fulfilment were the most frequent positive determinants of specific domains of QoL, while the inability to change one's living situation was the variable that most frequently had a significant negative effect on one of the QoL domains. Current heroin use was not retained as a significant determinant of QoL (not as a main effect nor as an interaction with one of the other independent variables) in any of the six regression models. A summary of the observed direct and indirect effects, according to the final path models, of current heroin use on different domains of QoL is reported in **Table 5.3**. The final path models of the six domains of QoL are presented in **Fig. 5.1** to **5.6**. Goodness-of-fit statistics of these models can be retrieved in **Table 5.4**. The model-fit statistics indicate an acceptable fit for all six domains of QoL, suggesting that the path models fit the data quite well.

Table 5.2: Sociodemographic and drug use-related characteristics of opiate-dependent individuals included in the study sample (*n* = 159)

Characteristics	Sample
Age [(*M SD*)]	36.6 (7.5)
Male (%)	74.8
Marital status (%)	
Unmarried	69.8
Married	7.5
Divorced/widowed	22.6
Intimate relationship (%)	45.3
Paid job (%)	26.4
Structured daily activity (%)	59.7
Inability to change living situation in the past year	74.2
Age at first use [(*M SD*)]	
Heroin	21.4 (5.6)
Methadone	26.0 (6.4)
Years of regular use [(*M SD*)]	
Heroin	10.8 (6.7)
Methadone	7.6 (4.4)
Injecting behavior (%)	
Ever	81.8
In the last 30 days	27.8
Heroin use in the last 30 days (%)	49.7
Duration of current methadone treatment episode (%)	
No current treatment	25.8
< 3 months	10.7
3-6 months	5.0
> 6 months	6.3
> 12 months	52.2
Average dose of methadone (%)	
No current treatment	25.8
1-39mg	27.8
40-59mg	25.9
60-109mg	16.5
> 109mg	3.8
Medication taken for psychological problems during the last year (%)	58.5
Physical complaints in the last 30 days (%)	66.5
Overall psychopathology	54.1

Table 5.3: Decomposition of effects of current heroin use on different domains of QoL

QoL domains	Direct	Indirect	Total indirect	Total
Health			-0.104 (p = 0.384)	-0.016 (p = 0.922)
(current heroin use, QoL)	0.088 (p = 0.517)			
(current heroin use, medication for psychological complaints, QoL)		-0.045 (p = 0.421)		
(current heroin use, fulfilment, QoL)		-0.094 (p = 0.127)		
(current heroin use, physical complaints in last 30days, QoL)		0.049 (p = 0.318)		
(current heroin use, satisfaction with treatment, QoL)		-0.024 (p = 0.685)		
(current heroin use, physical complaints, medication for psychological complaints, QoL)		0.021 (p=0.302)		
(current heroin use, fulfilment, medication for psychological complaints, QoL)		-0.012 (p=0.258)		
Living situation			-0.667 (p = 0.010)	-0.036 (p = 0.875)
(current heroin use, QoL)	0.631 (p = 0.014)			
(current heroin use, structured daily activity, QoL)		-0.495 (p = 0.003)		
(current heroin use, inability to change living situation, QoL)		-0.172 (p = 0.388)		
Family relations			-0.386 (p = 0.228)	-0.374 (p = 0.167)
(current heroin use, QoL)	0.012 (p = 0.974)			
(current heroin use, employment, QoL)		-0.619 (p = 0.112)		
(current heroin use, structured daily activity, QoL)		0.096 (p = 0.702)		
(current heroin use, age, QoL)		0.055 (p = 0.453)		
(current heroin use, employment, structured daily activity, QoL)		0.107 (p=0.704)		
(current heroin use, employment, age, QoL)		-0.025 (p=0.455)		
Leisure and social participation			-0.417 (p = 0.034)	-0.285 (p = 0.077)
(current heroin use, QoL)	0.132 (p = 0.470)			
(current heroin use, relationship, QoL)		0.028 (p = 0.760)		
(current heroin use, structured daily activity, QoL)		-0.249 (p = 0.015)		
(current heroin use, inability to change living situation, QoL)		-0.052 (p = 0.427)		
(current heroin use, fulfilment, QoL)		-0.091 (p = 0.136)		
(current heroin use, satisfaction with treatment, QoL)		-0.020 (p = 0.688)		
(current heroin use, fulfilment, structured daily activity, QoL)		-0.033 (p=0.198)		

Finances			-0.744 (p = 0.004)	-0.612 (p = 0.004)
(current heroin use, QoL)	0.132 (p = 0.593)			
(current heroin use, employment, QoL)		-0.379 (p = 0.013)		
(current heroin use, current methadone dose, QoL)		-0.290 (p = 0.039)		
(current heroin use, inability to change living situation, QoL)		-0.075 (p = 0.434)		
Safety			-0.326 (p = 0.123)	-0.125 (p = 0.493)
(current heroin use, QoL)	0.201 (p = 0.304)			
(current heroin use, positive self-esteem, QoL)		0.010 (p = 0.850)		
(current heroin use, currently in methadone treatment, QoL)		-0.298 (p = 0.024)		
(current heroin use, inability to change living situation, QoL)		-0.094 (p = 0.419)		
(current heroin use, physical complaints in last 30days, QoL)		0.078 (p = 0.247)		
(current heroin use, satisfaction with treatment, QoL)		-0.022 (p = 0.686)		

Table 5.4: Model fit indexes

Model	X^2	df	P	CFI	RMSEA
Health	5.351	4	0.2531	0.969	0.049
Living situation	0.062	1	0.8033	1.000	0.000
Family relations	0.099	1	0.7525	1.000	0.000
Leisure and social participation	11.213	7	0.1296	0.942	0.065
Finances	3.265	3	0.3525	0.995	0.024
Safety	9.192	9	0.4197	0.996	0.012

Health

In the final model for the 'health' domain, a direct effect of 'satisfaction with methadone treatment' (95% CI: 0.419 to 1.054), having a meaningful life (fulfilment) (95% CI: 0.403 to 1.059) and taking medication for psychological complaints (95% CI: -0.440 to -0.048) was found. However, no direct or indirect effects of current heroin use on 'health' could be demonstrated.

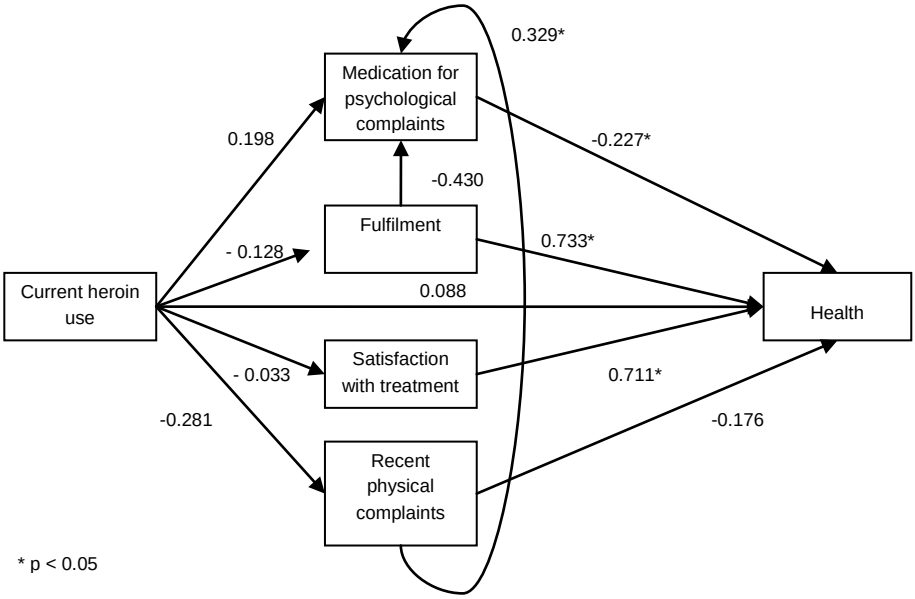
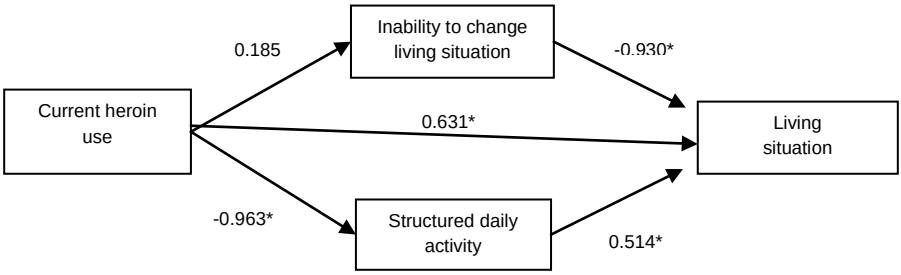


Fig. 5.1 Final path model for the domain 'Health'

Living situation

The 'living situation' domain was directly determined by having a structured daily activity (95% CI: 0.222 to 0.793), the inability to change one's living situation in the past year (95% CI: -1.132 to -0.689) and current heroine use

(95% CI: 0.115 to 1.160). Furthermore, the indirect effect of current heroine use on this domain was mediated by ‘structured daily activity’ (95% CI: -0.934 to -0.227).

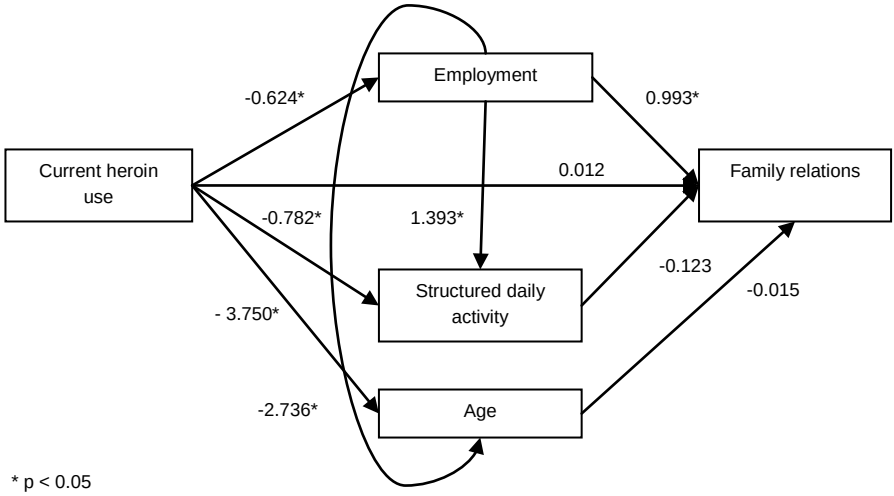


* p < 0.05

Fig. 5.2 Final path model for the domain ‘Living situation’

Family relations

Employment had a direct positive effect on the ‘family relations’ domain (95% CI: 0.104 to 1.983). None of the other direct effects, retrieved in the linear regression analysis, on this domain proved to be significant in the final path model. No direct or indirect effect of current heroin use on ‘family relations‘ was found.



* p < 0.05

Fig. 5.3 Final path model for the domain ‘Family relations’

Leisure and social participation

For the domain 'leisure and social participation', a direct positive effect was shown for being in a relationship (95% CI: 0.227 to 0.585), having a meaningful life (fulfilment) (95% CI: 0.269 to 1.066), having a structured daily activity (95% CI: 0.072 to 0.465) and satisfaction with methadone treatment (95% CI: 0.227 to 0.901). In addition, a direct negative effect of the inability to change one's living situation in the past year was observed (95% CI: -0.516 to -0.061) on this domain. Comparable to the domain of 'living situation', an indirect effect of current heroin use on 'leisure and social participation' was observed, mediated by 'structured daily activity' (95% CI: -0.522 to -0.066).

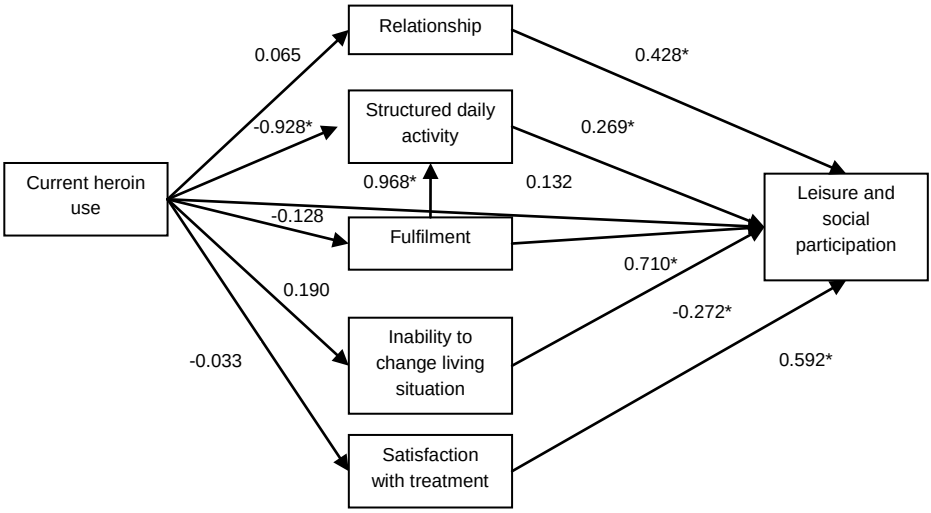


Fig. 5.4 Final path model for the domain 'Leisure and social participation'

Finances

Being employed (95% CI: 0.353 to 0.845), being unable to change one's living situation (95% CI: -0.675 to -0.151) and current methadone dose (95% CI: -0.715 to -0.183) were direct determinants of the 'finances' domain. Individuals with a current methadone dose between 40-59mg, reported significantly lower QoL scores for this domain than those no longer on methadone. No direct effect of current heroin use on this domain was found, but its total indirect effect (95% CI: -1.276 to -0.333), mediated through employment (95% CI: -0.704 to -0.136) and current methadone dose (95% CI: -0.625 to -0.081), together with the total

effect (direct and indirect) of heroin use (95% CI: -1.171 to -0.227) had a significant impact.

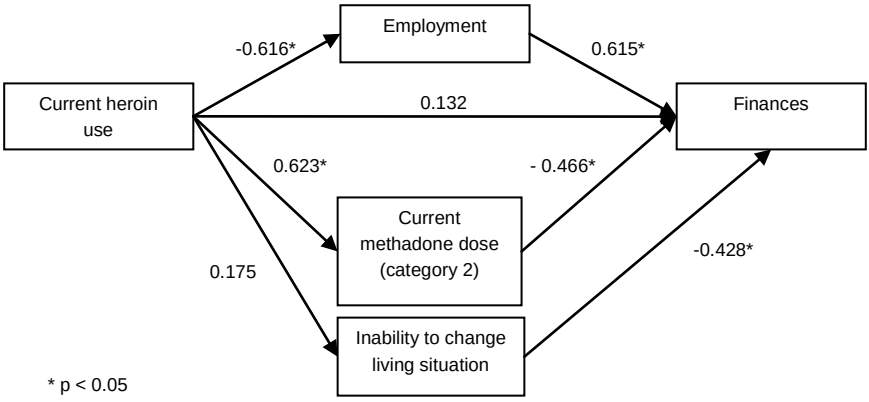


Fig. 5.5 Final path model for the domain 'Finances'

Safety

Higher scores for positive self-esteem (95% CI: 0.186 to 0.924) and satisfaction with methadone treatment (95% CI: 0.230 to 1.127) had a direct positive effect on the 'safety' domain, while the inability to change one's living situation in the past year (95% CI: -0.760 to -0.264), recent physical complaints (95% CI: -0.528 to -0.043) and currently being in methadone treatment (95% CI: -0.680 to -0.183) had a direct negative effect on the domain score. Also observed was a significant indirect effect of current heroin use, mediated by being currently in methadone treatment, (95% CI: -0.720 to -0.085) but no total or total indirect effect of current heroin use on 'safety' was retrieved (see **Table 5.3**).

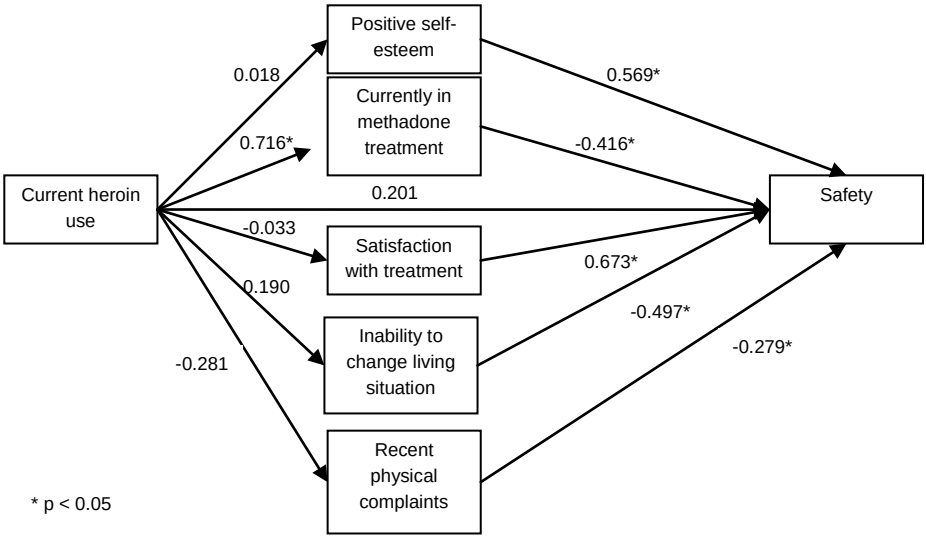


Fig. 6 Final path model for the domain 'Safety'

5.4 Discussion

5.4.1 Domain-specific determinants of QoL

This study of domain-specific determinants of QoL among opiate-dependent individuals revealed that none of the QoL domains studied were defined by the same compilation of determinants, illustrating the particularity of each QoL domain. Psychosocial variables (e.g. structured daily activity, employment, inability to change living situation) had a prominent impact on various domains of QoL, demonstrating the importance of supporting opiate-dependent individuals in every day life (De Maeyer et al., 2009). Greater satisfaction with methadone treatment was associated with better QoL scores in the domains of 'leisure and social participation', 'safety' and 'health'. This strong connection between satisfaction with services and QoL was also retrieved in the area of mental health care by Ruggeri and colleagues (2002), who found a positive association of satisfaction with services on all domains of the Lancashire Quality of Life Profile. A reason for the strong impact of satisfaction with treatment on QoL scores could be the subjective nature of both constructs, the so-called '*subjective appraisal factor*' (Fakhoury & Priebe, 2002; Ruggeri, Biggeri, Rucci & Tansella, 1998). Alternatively, it could be the fact that when treatment is experienced as satisfactory by an individual, this goes hand in hand with improved QoL (Ruggeri et al., 2002).

This study also reveals the influence of a number of person-related, psychological concepts (e.g. self-esteem, fulfilment) on opiate-dependent individuals' QoL. Various studies in mental health populations have demonstrated the importance of person-related variables (e.g. self-esteem, control, autonomy) on QoL (Bishop, 2005; Hansson et al., 1999; Barry & Zissi, 1997). Moreover, a recent study by Ponizovsky and colleagues (2010) found that perceived self-efficacy was an important predictor of QoL in opiate-dependent individuals following buprenorphine maintenance treatment. Improving clients' perceptions about themselves by increasing their personal control over their lives will result in improved QoL scores (Frain, Tschopp & Bishop, 2009). The positive association between 'meaningful life' and the domain of 'health' is noteworthy, illustrating that satisfaction with health is not restricted to health-related variables (e.g. medication for psychological complaints). Moreover, the impact of specific health-related factors was limited to the domains of 'health' and 'safety'.

Research on the effects of current substance use on the QoL of opiate-dependent individuals is very limited, but a few studies suggest a lack of direct effect (Conroy et al., 2008; Bizzarri et al., 2005). This study has elaborated on these findings. Notably, none of the clinical factors describing drug-related variables (e.g. duration of heroin use, injecting behaviour, recent cocaine use, recent heroin use) showed a direct association with any of the domains of QoL. Furthermore, no interaction effects were found between current heroin use and any of the domain-specific determinants of QoL. Although research has illustrated that the QoL of opiate-dependent individuals is lower than that of the general population and non-clinical control groups (De Maeyer et al., 2010), this study illustrates that lower QoL scores are not necessarily (directly) linked with recent heroin use. This finding strengthens the view that interventions for opiate-dependent individuals with a restricted focus on health and drug-related issues will only have a limited impact on the various domains of QoL. The findings emphasize the necessity for a more central position for psychosocial aspects and self-perception in QoL research than is afforded by a focus on strictly health-related aspects (Anderson & Burckhardt, 1999). A number of the retrieved determinants of QoL could be transformed into specific clinical interventions and attainable goals (e.g. improving housing situations), in order to enhance opiate-dependent individuals' QoL (Chan & Yeung, 2008). If we want to improve these persons' QoL, it will be important to focus on their personal life goals, starting from an individual, person-centred approach to support (Calman, 1984). An integrated and holistic treatment approach is necessary (Schalock & Verdugo Alonso, 2002), with attention to issues such as housing, vocational support, aspects of life meaning and psychological well-being.

5.4.2 Indirect effects of current heroin use on QoL

To the best of our knowledge, the study reported here is the first to investigate the indirect impact of current heroin use on QoL in opiate-dependent individuals by use of path analyses. The findings of this study suggest that the relationship between current heroin use and various domains of QoL is complex, and (mainly) indirect. Five indirect pathways were retrieved that showed an indirect effect of current heroin use on QoL. For the domains of 'living situation' and 'leisure and social participation', the indirect effect was mediated by the variable 'structured daily activity'. Opiate use, and heroin use in particular, often has a negative impact on individuals' daily activities, resulting in a rather unstructured life style or living situation (Fischer, Medved, Gliksman & Rehm, 1999; Reno & Aiken, 1993), explaining the negative correlation with 'structured daily activity'. These lifestyle problems show the need for long-term support with attention to rehabilitation, which goes beyond medical services and the delivery of methadone (Bobrova et al., 2007; Fischer, Chin, Kuo, Kirst & Vlahov, 2002). The effect of current heroin use was mediated by treatment-related variables in the domains of 'safety' (no total indirect effect) and 'finances'. For the 'finances' domain, current heroin use was partly mediated by a current methadone dose of 40-59 mg. In general, higher doses of methadone, with a minimum dose of 60 mg, are advised in order to achieve abstinence from heroin and longer treatment retention (Bao et al., 2009; Amato et al., 2005; Faggiano, Vigna-Taglianti, Versino & Lemma, 2003). Persons with low methadone doses might more frequently use heroin, resulting in high financial costs, explaining the indirect effect of current heroin use on the 'finances' domain, mediated by this specific dose of methadone. In addition, there was also a direct negative effect of a current methadone dose of 40-59mg on satisfaction in the 'finances' domain, which might be linked to the limited effectiveness of lower methadone dosage in promoting clients' control over their lives (Amato et al., 2005). The mediating role of 'employment' for current heroin use on the finances domain is not surprising, given the high unemployment rates among opiate users both in and out of treatment (Platt, 1995). This finding once again illustrates the importance of vocational support in treatment; a structured daily activity may have a positive impact on current use by creating a more structured lifestyle, with limited opportunities for relapsing into destructive patterns of drug use. Conversely, cessation of drug use may result in an improved employment status (Koo, Chitwood & Sanchez, 2007; Platt, 1995).

The findings of this study suggest that current heroin use is, among other characteristics, a risk factor for lower QoL, mainly due to its direct negative correlation with a number of psychosocial (e.g. structured daily activity, employment) and treatment-related variables. Furthermore, it is clear that the

impact of heroin use is more decisive in some domains than in others, indicating the need to assess QoL in a multidimensional way. This domain-specific, as opposed to global, approach to QoL is very useful in clinical practice and assessment, for acquiring knowledge in terms of clients' personal situation and for finding out in which domains specific support is needed in order to develop tailored interventions based on clients' needs (Pitkanen, Hatonen, Kuosmanen & Valimaki, 2009; Wu & Yao, 2007; Katschnig, 2006; Calman, 1984). This multidimensional approach to QoL will further promote the meaningful integration of the concept into clinical practice, by making it less abstract than the overall concept of QoL (Frost et al., 2007; Cummins et al., 2004) and stimulating the real value of QoL, namely to improve the well-being of individuals (Schalock et al., 2002).

5.4.3 Limitations

Some limitations of this study should be taken into account. First, the sample size (n = 159) was relatively small, limiting the generalization of our findings to other groups of opiate users. It is unclear if the sample was fully representative for the group of opiate-dependent individuals who started methadone treatment at least five years ago (n = 1,500), but the age and gender distribution of the sample was identical to that of persons in outpatient methadone treatment in the region of Ghent between 1997 and 2002 (Vanderplasschen et al., 2003). Second, due to the rather small sample it was not possible to create one broad path model which included all the different domains of QoL and determinants that influence these domains. For this reason, we decided to focus on the results of six separate path analyses. Third, because of the cross-sectional character of this study, it is unclear whether the models have predictive value. A study by Hansson and Björkman (2007) has illustrated that the importance of determinants of QoL may fluctuate over time, demonstrating the necessity for longitudinal studies. Future longitudinal research should address issues of directionality and linearity, in order to measure potential effects in both directions (Diener & Ryan, 2009). Furthermore, research should continue to explore the indirect effects of various forms of substance use and QoL and expand this exploration to other variables such as demographic ones (which are mostly measured directly). The higher prevalence of psychological problems, sexual and physical abuse and relational conflicts among women (Chatham, Hiller, Rowan-Szal, Joe & Simpson, 1999), and also the lower HRQoL scores among both women and older persons in methadone maintenance treatment (Haug et al., 2005; Lofwall, Brooner, Bigelow, Kindbom & Strain, 2005), may mediate potential indirect effects of age and gender on QoL. A fourth limitation is that there is a limited possibility of comparing these results with other studies. This limitation is due to the lack of a

common set of variables measured as potential determinants of QoL, the strong heterogeneity among the group of 'drug users' and the use of different instruments to measure the concept of QoL (De Maeyer et al., 2010; Ulengin, Ulengin & Guvenc, 2001). Retrieved predictors of QoL will be influenced by the instrument used and the way in which QoL is measured (Norman et al., 2000). Moreover, QoL is a subjective concept, influenced and determined by individuals' life experiences, making it difficult to determine 'standard/hard' predictors of QoL. This fact emphasizes the importance of individuals' personal stories and perspectives influencing their personal QoL, and also the need for more in-depth qualitative research.

5.4.4 Conclusion

This study extends our limited knowledge about (variations in) determinants of separate QoL domains in opiate-dependent individuals, illustrating the need for a multidimensional approach to the concept. The findings highlight the complex relationship between social, health, drugs and person-related aspects. The study also extends our knowledge of the impact of current heroin use on QoL by giving attention to possible indirect effects. Current heroin use in itself did not account for lower QoL scores, but its indirect effect on various domains of opiate-dependent individuals' QoL is an important finding, emphasizing the need to use statistical methods that allow the retrieval of indirect and mediated effects. Restricting QoL research to direct effects runs the risk of passing over the complexity of the concept. This study can have important implications for future substance abuse research and practice because it offers a starting point for a potential theoretical framework for the QoL of opiate-dependent individuals.

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Chapter 6

A good quality of life under the influence of methadone: A consumer perspective[5]

[5] Based on De Maeyer, J., Vanderplasschen, W., Camfield, L., Vanheule, S., Sabbe, B., & Broekaert, E. (submitted). A good quality of life under the influence of methadone: A consumer perspective. Submitted for publication in International Journal of Drug Policy.

Abstract

Objective: The amount of attention paid to the quality of life (QoL) of opiate users is growing, but these studies are mainly quantitative, giving limited attention to the consumer's perspective. This qualitative study aims to expand our knowledge concerning opiate-dependent individuals' perceptions of the components of a good QoL and the impact of methadone on these components.

Methods: In-depth interviews were conducted with 25 opiate-dependent individuals, ranging from 26 to 46 years old. Purposive sampling was used to recruit participants with different treatment profiles and socio-demographic characteristics. The interviews were tape recorded, transcribed verbatim and analysed thematically.

Results: Thematic analyses revealed five key themes contributing to a good QoL for opiate-dependent individuals, including having social relationships, holding an occupation, feeling good about one's self, being independent and having a meaningful life. Opiate-dependent individuals valued methadone's ability to help them function normally, overcome their psychological problems and dependence on illicit opiates, and support them in achieving certain life goals. On the other hand, stigmatisation, discrimination, dependence on methadone and the drug's paralysing effects on their emotions were mentioned as common negative consequences.

Conclusion: The findings of this study highlight the importance of supporting opiate-dependent individuals in their daily life by means of practical, social and environmental support (alongside pharmacological treatment) with the aim to improve their QoL. This study further illustrates the ambivalent influence of methadone on opiate-dependent individuals' QoL, and demonstrates how something commonly perceived as a 'good' can also be a 'bad' for some people. Efforts should be made to limit the negative consequences of methadone on opiate-dependent individuals' QoL, while increasing its potential benefits.

"Three grand essentials to happiness in this
life are something to do, something to love,
and something to hope for."
Joseph Addison (1672 - 1719)

6.1 Introduction

Over the last two decades, the growing attention paid to the consumer's perspective in health care has been noticeable (McKeganey, Morris, Neale & Robertson, 2004; Wiklund, 2004; Smith, Manderscheid, Flynn & Steinwachs, 1997). In contrast with other fields (e.g. mental health, cancer research), drug users have not been seen as important sources of information and their personal perspectives about substance abuse treatment and their life in general are not widely reported in the literature (Kolind, 2007; Drumm et al., 2003; Montagne, 2002; Brun & Rapp, 2001; Hunt & Barker, 1999; Neale, 1998). Furthermore, the majority of studies on substance abuse tend to start from a problem-oriented focus without paying attention to the strengths and abilities of individuals (Stajduhar, Funk, Shaw, Bottorff & Johnson, 2009; Saleebey, 1996).

One concept strongly focusing on individuals' personal perspectives and strengths is the notion of quality of life (QoL) (King & Napa, 1998; Diener & Suh, 1997). Only recently has QoL begun to receive attention in the field of substance abuse research, in particular among opiate-dependent individuals (De Maeyer, Vanderplasschen & Broekaert, 2010; Zubaran & Foresti, 2009). Given the subjective nature of the concept of QoL, opiate-dependent individuals' own experiences should be the starting point for QoL research in this field (Carr & Higginson, 2001; Fischer, Rehm & Kim, 2001a; Bonomi, Patrick, Bushnell & Martin, 2000). Like other marginalised groups, the perspectives of drug users on QoL have been largely ignored (De Maeyer, Vanderplasschen & Broekaert, 2009; Corring & Cook, 2007). There are few studies on the effects of drug use on QoL, and those that do exist are mainly quantitative and rarely user-led (Rudolf & Watts, 2002; Fischer et al., 2001a). As a consequence, outcomes in QoL studies are mostly measured according to what is important to health care professionals rather than to the users themselves, which may account for the poor performances of such measures (Gilbert, 2004; Carr & Higginson, 2001; Fischer, Rehm & Kim, 2001b). Quantitative studies can hardly capture the complex and idiosyncratic impact of drug use on people's lives. Furthermore, research into which factors constitute the QoL of opiate-dependent individuals is limited and also restricted to a number of quantitative studies (De Maeyer et al., 2010). One of the limitations of these studies is that only a small part of the statistical variance of QoL is explained by the included predictors, leaving a blind spot on other aspects that may have an impact on opiate users' QoL.

This exclusive focus on quantitative research is further found in studies on the effectiveness of methadone treatment in improving opiate users' QoL (De Maeyer et al., 2010). In these quantitative studies methadone maintenance treatment has been found to be effective in reducing heroin use, prolonging treatment retention and improving QoL (De Maeyer et al., 2010; Mattick, Breen, Kimber & Davoli, 2009; Amato et al., 2005). However, limited qualitative research is available on client perspectives on the impact of methadone on their overall functioning (Fischer, Chin, Kuo, Kirst & Vlahov, 2002; Neale, 1998), and QoL in particular. Since methadone substitution treatment is the standard, evidence-based treatment for opiate dependence in many countries, attention should be given to the influence of this treatment form on opiate users' daily lives (Amato et al., 2005). If one of the goals of methadone treatment is to improve the QoL of opiate-dependent individuals, then it will be important to involve these clients in participatory research on the concept QoL, so that they can be part of the process rather than sideline spectators (Enriquez et al., 2005; Ruefli & Rogers, 2004).
Given the complex nature of QoL, and its uniqueness to each individual, it should be investigated using several approaches, including qualitative methods (Serber & Rosen, 2010; Katschnig, 2000). Qualitative research can provide more in-depth information about quantitative study results (Serber & Rosen, 2010; Fountain & Griffiths, 1999), which are often limited to the average scores of a specific sample, and can explore aspects of QoL not yet probed by quantitative research (Camfield, Crivello & Woodhead, 2009). Moreover, qualitative research based on a bottom-up approach is most appropriate to focus on an individual's subjective experiences (Davidson, Ridgway, Kidd, Topor & Borg, 2008; Neale, Allen & Coombes, 2005; Ager & Hatton, 1999), which is one of the basic components of QoL investigation (Moons, Budts & De Geest, 2006).

A qualitative approach, through the use of in-depth interviews, was used in this study to answer the following research questions: 'Which components identify a good QoL for opiate-dependent individuals?' and 'What is the impact of methadone on those components?'. The aim of this study was to gain more in-depth knowledge about the themes that opiate-dependent individuals consider important in attaining a good QoL and how methadone can negatively or positively influence those themes. By focussing on positive moments in opiate-dependent individuals' lives, this study starts from a strengths-based standpoint rather than taking a problem-oriented approach.

6.2 Methods

6.2.1 Sample

This qualitative study is part of a larger research project on QoL of opiate-dependent individuals who started methadone treatment five to ten years ago in the region of Ghent (Belgium) (*n* = 159). The methodology of this study is extensively described elsewhere (De Maeyer et al., in press). At the time of the interviews, participants were asked if they were willing to participate in the qualitative phase of this research project on QoL and the role of methadone treatment. One hundred and fifty-four participants volunteered to participate in continuing/follow-up research (96.4%). Purposive sampling (Patton, 1990) was used to ensure that a range of different QoL experiences were included, in order to generalise our results. We included opiate-dependent individuals both in and out of treatment, with various levels of heroin use (e.g. daily use, irregular use, no use), and different socio-demographic characteristics that could possibly influence their QoL (e.g. age, gender, employment) (De Maeyer et al., 2010). The sample of this study included 25 participants with ages ranging from 26 to 46 years old, with a mean age of 34.6 years (SD = *5.2)*. One third of our sample were women (32.0%). Seventeen participants (68.0%) were still following a methadone treatment at the time of the interview. The characteristics of our 25-participant sub-sample were comparable with the total sample of the research project.

6.2.2 Data collection

The majority of the interviews (*n* = 22) were conducted by the first author, the remaining interviews (*n* = 3) were administered by a last-year student in educational sciences under the supervision of the first author. The qualitative interview took place after repeated contact with the participants, resulting in a higher degree of trust. Data were collected through audio-recorded, open-ended interviews that took place in participants' houses, public places and treatment centres. Interviews lasted approximately 40 to 120 min. and were administered between September 2008 and August 2009. Individuals received €20 for participation in this qualitative study. A written informed consent was obtained from all participants before starting the interview. Participation was entirely voluntary and confidentiality was assured. The study was approved by the ethical committee of the Faculty of Psychology and Educational Sciences of Ghent University in accordance with internationally accepted criteria for research (2006/51).

At the beginning of the interview, participants were asked to think about the period in their life, from the moment they started their methadone treatment until the present time, when their QoL was the highest and to describe important components that contributed to this period. Afterwards, they were asked to discuss the impact of methadone (positive or negative) on those components. These two questions were the only structure used in the interview, because we wanted to give participants the freedom to start from their own frame of reference rather than accommodating to a strict structure. Participants were asked to narrate their personal experiences in their own way. Based on these experiences, the components of QoL were further explored.

6.2.3 Data analysis

Thematic analysis was used to analyse our qualitative data. This technique is a method for finding patterns of meaning across qualitative data (Braun & Clarke, 2006). An inductive (bottom-up) approach was used, data-driven, without pre-supposing important themes in advance (Braun & Clarke, 2006; Rhodes & Moore, 2001; Patton, 1990). The interviews were transcribed verbatim, read several times and the most outstanding themes were identified. A second level of analysis was done to identify if certain themes contained possible sub-themes. A line by line analysis of the manuscripts was completed by the first author, noting similarities and differences. Dominant themes in the factors contributing to QoL and the impact of methadone on those themes were identified. A cross-case analysis was used to compare information represented in individuals' perceptions in the various interviews and to identify patterns across the different participants (Patton, 1990). These themes and sub-themes were used as a classification system to code our data (Kolind, Vanderplasschen & De Maeyer, 2009). The transcripts and emerging themes and sub-themes were reviewed by the second author to ensure external validation of the data analyses. Each theme is illustrated by a number of quotes from the interviews. To avoid estrangement of the data and to gain in-depth insight into the aspects of analysing qualitative data, analyses were done manually instead of by use of a computer-assisted qualitative data analysis software (Webb, 1999).

6.3 Results

The data-analysis revealed five main themes, as well as several sub-themes, as important components of a high QoL. The five themes were: having social relationships, psychological well-being, having an occupation, being independent and having a meaningful life, and included sub-themes, such as support and a positive self-image. In **Table 6.1**, an overview is given of themes and sub-themes important for a high QoL and whether methadone had a positive or a negative impact on them. In what follows, we will describe in detail these components and methadone's impact on them.

Table 6.1: Themes and sub-themes derived from thematic analysis of qualitative data
(+) positive impact, (-) negative impact, (-/+ both positive and negative impact)

Themes	Sub-themes	Impact of methadone
Having social relationships	Support Social integration Sense of belonging Responsibility	Stigma/discrimination (-) Being able to take responsibilities (+) Being able to function normally/integrate into society (+)
Psychological well-being	Coping Positive self-image Inner rest/peace of mind Emotional stability	Paralysing effect on feelings (-/+) Getting control over psychological problems (+) Freedom from worry (+) Being able to take a break (+)
Having an occupation	Preventing boredom Replacement for their drug use Contributing to society Social contacts Increased self-esteem	Being able to do a job and keep it (no withdrawal) (+) Low-quality jobs (-)
Being independent	Gaining control over their life Independent of drugs Financially independent Independent of others (partner, family)	Dependence on methadone (-) Restriction of their personal freedom (-) Vicious circle (-) Enhancement of their financial independence (+) Controlling their opiate use (+)
Having a meaningful life	Stability and security (e.g. settling down) Enjoying small things Feeling useful and meaningful New start Future perspectives • Goals and prospects • Personal development	Recovering stability and structure (+) Support in achieving life goals (+) Limited impact, substitute for heroin use (-) Transitional stage (-/+)

6.3.1 Social relationships

The positive impact of having personal relationships on an individuals' QoL was raised in all interviews. Participants frequently cited that the presence of a good friend, children, or a supportive, caring partner was very characteristic for the period in their life with the highest QoL.

> *"The time I had a girlfriend really stands out. She had a little kid of two years old. I was really happy that I could help her bringing up her kid. That was a really good time; going for a walk in the park, playing football, doing fun things. And my girlfriend really understood me, we could talk for hours."* (Man, 35 years)

The availability of social contacts and the importance of becoming socially active were highlighted by various participants. Being integrated to and supported in society, or even only in their immediate environment, had a positive impact on their QoL, including feelings of acceptance and respect. The presence of like-minded people often created a feeling of solidarity and a sense of belonging.

> *"Friendship has always been important to me, a good conversation means so much more than whatever form of medication. I can't explain it, but friendship is a sort of recognition for me. It makes me feel I am part of the world again."* (Man, 38 years)

Maintaining relationships also resulted in feelings of responsibility and taking care of someone (e.g. partner, children). Those feelings enhanced individuals' self-esteem, resulting in a better QoL. Therefore, the directionality of social networks is not unilateral as people valued not only receiving support, but also sharing nice moments and taking responsibility for others.

Impact of methadone

When talking about the influence of methadone on social relationships, participants frequently cited the negative impact of stigma on their social integration. When opiate-dependent individuals are open and honest about the fact they are taking methadone, this often results in negative reactions (in their direct environment) based on stereotypes. Opiate-dependent individuals often experience feelings of stigma in their daily life, for instance, when they need to go to the pharmacist to publicly drink their methadone. Opiate-dependent

individuals have the feeling family and employers do not know what methadone actually is; for them, it is also a drug and goes hand in hand with a deep distrust of the people using it.

> *"People don't trust you, when you take that kind of medicine [methadone]. Imagine you're having a talk with someone, and you tell them you're on methadone. Immediately, they put their wallet in their pocket, because they don't trust you. That's how it goes. It does not help you with your social contacts."* (Man, 38 years)

Those negative, social experiences interfere with opiate-dependent individuals' sense of belonging and their social inclusion. One participant considered himself as 'a problematic case' as long as he was taking methadone because he felt 'different' than 'normal' people. For other participants, taking methadone is a personal secret they carry with them because they are afraid of the social consequences of openly admitting their methadone use.
Despite the negative impact of methadone treatment on important aspects of this theme, methadone helped opiate-dependent individuals take responsibility for their children, one of the most important components of their QoL. For some respondents, being on methadone prevented their children from being taken away and placed in foster families.

> *"I set my alarm one hour in advance for seven o'clock. I knew it took one hour before my methadone started to work and at eight o'clock I brought my daughter to school."* (Man, 39 years)

Furthermore, methadone supported opiate-dependent individuals' integration, because they were able to function normally (e.g. being able to have a job) and operate in society. Often, those participants kept their methadone use secret.

6.3.2 Psychological well-being

When participants told the interviewers about the best period in their lives since they started taking methadone, this involved a general feeling of psychological well-being or "feeling good about yourself". A number of participants mentioned the need to be able to cope with emotions and incidents that happened in the past in order to achieve this feeling of psychological well-being. Psychological well-being was also strongly correlated with a positive self-image. When individuals were able to become clean or achieve something in life, this often involved a feeling of satisfaction and increased feelings of self-esteem. Increased self-

respect also resulted in more intensive self-care (e.g. taking care of their body, well-cared for appearance, and healthy eating).

> *"I never achieved something, I never completed any form of education, I really lacked any form of self-esteem. Then, I was determined to finish something, and I achieved a certificate of bricklayer. It was at least something. And I finished it this time. That was proof to myself that I was able to do something, and from that moment I started to change."* (Man, 36 years)

This general feeling of psychological well-being also contained a state of inner rest and emotional stability. In the past, this inner rest was frequently obtained by the use of heroin (or medication), resulting in a brief feeling of inner rest.

> *"I feel really good about myself, I've never felt that way. I am satisfied with myself and with my life. It's all about feeling good about myself, emotionally, psychologically, I'm balanced. I became stable, I know much more what I want in life, who I am, yeah, I'm really stable now and that gives me an enormous feeling of inner rest. I've always been looking for tranquillity of mind; somebody who uses drugs is very restless, there's a reason why they use drugs."* (Woman, 30 years)

Impact of methadone

Both negative and positive effects of methadone were reported on psychological well-being. A large number of the participants cited the paralysing impact of methadone on their emotions. This restriction of feelings made it impossible to fully enjoy life and lowered their QoL. One participant described it as "tying a knot in his feelings". On the other hand, the same person mentioned that when taking heroin, his feelings were also limited to "scoring drugs", illustrating that his situation before taking methadone was worse.

> *"The last 10 years, I was taking doses of 100mg or more, it stunned me. I had no pain; I lived on automatic pilot, but nothing more. Nothing or nobody was able to make me feel something, neither good, nor bad. I would rather feel bad now and then, so that I'm able to feel good once in a while, than always living on automatic pilot."* (Man, 39 years)

For a limited number of opiate-dependent individuals, methadone contributed to a stabilisation of their psychological well-being and enhanced their coping abilities, e.g. because psychological problems caused by their heroin use (e.g.

psychoses, paranoia) were under control or less intense. Taking methadone does not take away the reason why people start taking drugs (e.g. inner rest, coping with emotions), but it temporarily puts a film on those feelings. For some participants this blockade created the possibility of first dealing with other problems (e.g. practical issues) affecting their QoL.

> *"Because of my methadone, I had more moments that I was able to deal with it. Without that methadone, I was deeply unhappy and depressed. With methadone, step by step things were getting better. I became more stable. Certain feelings were paralysed, that's my experience, a certain warmth inside of you. Even when I was feeling completely on my own, methadone made this feeling less intense."* (Man, 36 years)

A number of people cited that methadone indirectly brought a certain feeling of peace of mind and body, because they were no longer confronted with the direct consequences of their drug use (e.g. financial problems, looking for drugs, or being sick).

6.3.3 Structured daily activities

Having an occupation had a prominent place in opiate-dependent individuals' stories about the time they experienced their highest QoL. Various reasons are given to demonstrate the importance of 'having something to do'. First of all, being occupied with something (e.g. work, hobbies, training) prevents individuals from being bored.

> *"My job is very important to me, I don't want to be on welfare again, being home the whole day, one month and I will be right down in the dumps."* (Woman, 34 years)

When people stop using drugs, this can leave a great emptiness, and having a job or a daily activity was often a replacement for their drug use, or at least took their minds of using drugs. Most participants were heroin-free during the time that their QoL was the highest, but this was only a prerequisite for a good life. A replacement for their drug use (e.g. family life, job, motorcycle) was essential to actually enhance their QoL.

> *"I was really sporty, I trained a lot. Maybe it's not noticeable anymore, but I had enormous muscles. I needed a form of addiction, but a positive one. I really felt good about myself; those were the best years of my life."* (Man, 38 years)

What is more, it is not only having something to stay occupied that is important, but also the meaning that is attached to that occupation (e.g. recreation, emotional release, expanding their social network). Having a job for instance, resulted in higher self-esteem and a positive self-image, because participants felt responsible and that they were contributing to society instead of being 'a lazy junkie'.

> *"It's important for me that I have a job with a lot of responsibilities. I have an executive function, and that's very good for my self-image, because my self-confidence took a terrible knock in the last 10 years."* (Man, 28 years)

Impact of methadone

The positive impact of methadone on daily activities was most noticeable for making it possible for an individual to practise a job. By taking methadone, some participants were able to keep their jobs, despite the fact they were using heroin on a daily base. Being able to continue working also prevented participants from falling into a sort of limbo that carried the risk of relapse into (even more) excessive heroin usage.

> *"It also makes a difference for your job. When you have no dope, and you need to go to work, that's just not possible. But now, you just drink your methadone and off you go. For that, it helps a lot. You're able to do your job and be busy."* (Man, 27 years)

Nevertheless, side-effects often restricted them concerning the jobs they were able to do. A participant explained that although with methadone he was able to work, these were all jobs below his standards and he did not fully use his capacities.

6.3.4 Independence

Being independent is one of the most important components of a high QoL for opiate-dependent individuals. Most participants have been dependent on opiates for many years, resulting in a lower QoL. The majority of the participants' best

periods since they started taking methadone was characterised by being clean and independent of any substance.

> *"In my head, I'm an anarchist. I always want to have the feeling that I'm free. When you're dependent on something, this always lowers your quality of life. When I'm not free, I can't be happy. You're always dependent on something anyhow, but for god sake not on some stupid powder?"* (Woman, 26 years)

The use of drugs can have a positive impact on QoL (in the short-term), but because their heroin use resulted in a strong dependence, recreational use was no longer an option for the majority of participants.

> *"In general, I think the use of stimulants can have a place in a life of high quality, absolutely. Before I was dependent on heroin I also took other products, but very moderate, I could deal with that to a certain extent, and I really enjoyed it. But now, things are different. I am an ex-junkie, you know, and it's just not for me anymore."* (Man, 28 years)

Being independent resulted in a feeling of gaining control of their lives and standing on their own feet, resulting in a strong sense of self-efficacy. Participants' stories about the importance of independence were not limited to independence from drugs. They also cited the significant impact of being financially independent, and the possibility of experiencing a feeling of well-being on their own, without being dependent on a partner.

> *"That's one of the biggest changes in my life, the fact that I now exist on my own and that I'm not dependent on anyone. I'm happy because of all those aspects I created myself."* (Woman, 30 years)

Impact of methadone

The impact of methadone on the theme of independence is very ambivalent. On the one hand, methadone can have a positive impact on the financial situation of individuals, because it is much cheaper than heroin and quite easy to obtain. This might result in an enhancement of their financial independence and keeps them from ending up in illegal situations while trying to get money to buy 'dope'.

> *"When I started my methadone treatment, I was really happy that I wasn't sick anymore, especially when I ran out of money. Then I could*

> *get things under control again. When I was short of money to buy heroin, I always had my methadone."* (Man, 35 years)

Another positive aspect of methadone is that it limits dependence on illicit opiates by making opiate-dependent individuals no longer sick when they are not using heroin, increasing their control over their heroin use. However, at the same time, a new dependence on methadone is created.

> *"If there hadn't been methadone, I would have never managed without those drugs, because my drug use would have always come first. And with methadone, I could function without the need to take drugs. That helped, but I did have the feeling I was tied down to methadone."* (Man, 39 years)

The practical and institutional dependence on methadone, together with a long treatment duration and heavy withdrawal, restrict individuals' personal freedom. Moreover, by taking methadone participants were unable to leave their past behind and gave them the feeling that they were still part of the drug scene, resulting in a vicious circle.

> *"I would like to end it, but it's not possible. Each time I need to go there [the methadone centre], I always run across those (ex-)junkies. It's really shocking. I have moments that I have the feeling I'm still right in the middle of it. You are forced to take it every day. I try to put it off, but I can't deal with it physically. I would like to end it, but it's living inside of you."* (Man, 36 years)

Take-home doses of methadone were mentioned as a way to improve their QoL and control their methadone dependence. Finally, becoming methadone-free was one of their major victories in life.

> *"I found it terrible with my philosophical ideas to be dependent on methadone. I didn't want to be dependent on anything any longer, and especially not a tablet of methadone. Every morning, those 2 or 3 tablets, I was really sick of it. And then, all those times you forgot to take it, or a closed pharmacy, or not being able to reach my doctor, then I really had a hard time, panicking and running myself into a sweat. […] I'm so happy that's no longer the case, because it determined my whole day, your whole life, continuously, and that has been such a relief, I'm really satisfied with it."* (Man, 37 years)

6.3.5 Meaningful life

Having a meaningful life was associated with settling down, the security of a family and striving for stability in life (e.g. financial security, housing, basic comfort). In general, opiate-dependent individuals' expectations about life are low. In particular, the importance of enjoying the small, ordinary things in life (e.g. walk in the park, eating an ice cream) was frequently mentioned.

> *"Happiness is being happy with what you've got, and when you've been living in a situation 10 centimetres under hell, from the moment you're a few centimetres above, you'll be happy."* (Man, 46 years)

Purposeful living is strongly connected with having daily activities that a person is interested in and that make them feel useful. After many years of isolation, it is important for these individuals to feel that they actually mean something in this world.

> *"I need the feeling that I mean something for society. I know my place, but I want to be somebody, I don't want to stand on the side line, being a drug user or needing my methadone. It's also important I can mean something for myself and that I am able to attain something."* (Man, 39 years)

An important sub-theme that was mentioned frequently when talking about a meaningful life was the importance of having future perspectives, about which two important aspects emerged from the interviews. First, the existence of future goals and prospects is significant. Lacking concrete future goals in life can result in a desperate situation, through which individuals linger in a vicious circle of hopelessness. One of the participants called it "the need for a small plan he could strive for".

The second important aspect connected to future perspectives is the ability to further develop one's personality and discover new things by broadening one's horizons. The importance of travelling has been cited by several individuals as a way of discovering and experiencing new aspects of life. This was often linked with the necessity to start all over again in another environment, without prejudices and with a clean slate.

Impact of methadone

Methadone had a positive impact on recovering the stability and security in opiate-dependent individuals' lives. By taking methadone, individuals were able to deal with certain problems (e.g. financial, relational), preventing further

escalation of their situation. While taking methadone, opiate users could step off 'the roller coaster of drug use' for a moment and take time to think about their lives (from a more long-term perspective). Methadone could provide the stability and the necessary balance some people needed to get their lives back on the right track and further develop their life plans.

> *"Methadone can give you the time and the necessary space to reflect on your life, and to think for a moment what you are doing with your life. Otherwise, it's an automatism to score, to take drugs; and if you can stop this for a while, because of methadone, that's a good thing."* (Man, 30 years)

For some participants methadone supported them in achieving certain life goals that were important to them.

> *"I graduated on methadone, absolutely, and also during the exams I did not take any dope, nothing, maybe a joint, but apart from that only methadone. For 4 weeks, I didn't use any drugs, except my methadone. I was really stern with myself, because I really wanted my certificate, but without methadone, I would have probably never graduated."* (Woman, 30 years)

Notwithstanding the above mentioned benefits of methadone, a number of participants mentioned methadone's limited impact on achieving a meaningful life, stating that they experienced methadone purely as a substitute for their heroin use. They cited the importance of psychosocial counselling, alongside their pharmacological methadone treatment, to support them in achieving a meaningful life. Dependence on opiates often has a negative impact on various life domains, and methadone alone is not enough to completely change a lifestyle and create the right conditions for a meaningful life.

> *"I don't think there's one form of medication that makes you happy. Happiness, you have to make by yourself, you have to look for it. I don't think methadone makes you happy, because you have so much misery, with all other aspects in your life."* (Man, 34 years)

For most people, a meaningful life involved being drug and methadone free, but methadone was seen as a 'middle-stage' in this life-long process.

"When I took my methadone, and my dose was okay, I was able to do my job, with my family things were going well. Now I realise it was not completely natural, but it was bearable, I could manage, and I was able to deal with people. So in this respect, it helped a lot to tide me over for a certain period." (Man, 37 years)

6.4 Discussion

Based on this in-depth study of the personal stories of opiate-dependent individuals on important components of a high QoL, we identified five key themes contributing to a good QoL. Opiate-dependent individuals' periods of time with the highest QoL were characterised by the availability of supportive and caring relationships, having an occupation, high psychological well-being, being independent and having a meaningful life.
The availability of *supportive relationships* has been one of the major themes in this study. It demonstrates a clear contextual component in opiate-dependent individuals' QoL, and urges for attention to be paid to a person's social life in methadone treatment, alongside their psychological functioning (Heinz, Wu, Witkiewitz, Epstein & Preston, 2009; Gogineni, Stein & Friedmann, 2001). Marital counselling and family therapy can be very productive complements to methadone maintenance treatment, helping to enhance opiate-dependent individuals' QoL by supporting the development of their social network (Heinz et al., 2009; Fals-Stewart, O'Farrell & Birchler, 2001; Gogineni et al., 2001).

Furthermore, feeling good about yourself and having a *balanced psychological well-being* were often the starting point for a good QoL, which is comparable with findings of qualitative studies in mental health research (Pitkänen, Hätönen, Kuosmanen & Välimäki, 2009; Michalak, Yatham, Kolesar & Lam, 2006). This is not surprising, given the high occurrence of psychiatric co-morbidity in opiate-dependent individuals (Carpentier et al., 2009; Cacciola, Alterman, Rutherford, McKay & Mulvaney, 2001), which often results in a number of restrictions (e.g. social exlusion, stigma) affecting individuals' QoL. This points out the necessity of addressing the popular prejudices which lead to people being stigmatised (Radcliffe & Stevens, 2008) and the need for an integrated treatment of drug dependence and mental health problems (Drake, Mueser & Brunette, 2007).

In addition, *purposeful living* was cited as one of the most important components for a good QoL. Feeling useful and being able to give something back to society bring about positive life events and feelings of empowerment, both connected

with experiencing a higher QoL (Davidson, Shahar, Lawless, Sells & Tondora, 2006). Purposeful living was strongly connected with personal development and growth. Creating possibilities for personal development not only results in a higher QoL, but brings about more positive feelings regarding the effectiveness and benefits of methadone treatment (Gourlay, Ricciardelli & Ridge, 2005). While the importance of meaningfulness for QoL has already been demonstrated in the literature (Debats, Drost & Hansen, 1995; Harlow & Newcomb, 1990), it receives limited attention in clinical practice. This might be due to the strong subjective character of a meaningful life, making it hard to measure from an objective approach (Debats et al., 1995). Nevertheless, interventions in the field of substance abuse that give attention to future goals and meaningfulness in life and counter the discrepancy between an individual's current situation and their hopes and expectations, are likely to increase satisfaction in various life domains (Irving, Seidner, Burling, Pagliarini & Robbins-Sisco, 1998).

The urge for *independence* has been another key finding in this study that has received little attention in previous research on opiate users' QoL (De Maeyer et al., 2010). However, in (mental) health care research, the importance of independence on individuals' QoL has been frequently demonstrated (Michalak et al., 2006; Pickens, 1999; Dale, 1995). One of the most successful ways to increase feelings of control and independence is by supporting opiate-dependent individuals in finding a job, which goes hand in hand with increased self-esteem and a feeling of financial independence (Ruefli & Rogers, 2004). Supporting individuals through *vocational therapy* and financial aid increases their feelings of control and sense of mastery over their lives, once more resulting in their empowerment (Frain, Tschopp & Bishop, 2009; Rosenfield, 1992).

Notably, the quoted themes involving high QoL are *universally relevant*, as much among people with opiate dependence as among people with mental health problems and the general population (Diener & Ryan, 2009; Corring & Cook, 2007; Michalak et al., 2006; Pickens, 1999). Moreover, it was remarkable that the same themes were cited by people both in and out of treatment, as well as by those with different levels of use. This generic character of the themes is not surprising since, beyond being dependent on drugs, these individuals also fulfil diverse social roles (e.g. partner, parent, employee) that are part of everyday life (Neale, Bloor & McKeganey, 2007). Further, as with people with mental illnesses (Corring & Cook, 2007; Pickens, 1999), opiate-dependent individuals hold a strong 'desire for normalcy'.
Nevertheless, as demonstrated in this study, the interpretations of those themes and the factors influencing them might be specific to a certain population (in this case, opiate-dependent individuals). Opiate-dependent individuals have (to be

able) to cope with a number of limitations (e.g. social isolation, psychological problems, stigma), which are often a result of their drug using lifestyle and function as barriers to achieve a 'normal life' (Woods, 2001). When working with opiate-dependent individuals, social workers and QoL researchers should be sensitive to the impact of these, often long-lasting limitations that are beyond the direct consequences of drug use. Therefore, a comprehensive and continuing care approach, with attention for individuals strengths and abilities is a must (Vanderplasschen, Bloor & McKeganey, in press; Hess, Vanderplasschen, Rapp, Broekaert & Fridell, 2007; McLellan, 2002). Furthermore, this study demonstrates the holistic character of the concept QoL (Michalak et al., 2006; Schalock et al., 2002). Themes were often interconnected and could not be assessed in a linear way, instead urging an integrated treatment form that looks at the broader context of QoL (Schalock et al., 2002).

Paying attention to only the pharmacological and medical impact of methadone, without observing its influence on opiate-dependent individuals' QoL, will result in a one-sided representation of this treatment form (Neale, 1998). Methadone treatment is a social intervention as well as a pharmacological treatment, and therefore may have adverse effects unrelated to its success as a chemical substitute for heroin.

Participants' attitudes towards the impact of methadone on QoL were characterised by a *strong ambivalence*, demonstrating the complex nature of this treatment form (Neale, 1998). The *positive impact* of methadone on daily life cited in the interviews, corroborated with findings of previous research (Fischer et al., 2002; Neale, 1998). Gaining control over one's life and daily functioning and no longer being sick when no heroin is available, were only few of the frequently mentioned benefits of following a methadone treatment. These findings illustrate the potential of methadone treatment to create the necessary preconditions (e.g. control) to deal with a number of issues (e.g. developing one's skills to practice a job) that can enhance individuals' QoL. Taking methadone itself does not always result in drastic changes, but can have a positive impact on a number of themes (e.g. relationships) that contribute to a good QoL.

Conversely, a number of consequences (e.g. heavy withdrawal effects, stigmatisation and dependence) were mentioned as having a *negative impact* on important aspects of QoL. Being dependent on methadone is an issue frequently mentioned in the literature (Järvinen, 2008; Holt, 2007; Fischer et al., 2002; Neale, 1998) and the impact of *methadone dependence* on QoL should not be underestimated. Institutional and practical dependence restrict opiate-dependent individuals' freedom and are often accompanied by anxiety about a chronic dependence on methadone (Holt, 2007, McKeganey et al., 2004). Given their

histories of dependence on drugs, a dealer, or a using partner, this replaced feeling of dependence strongly limits opiate-dependent individuals' feelings of overall well-being. Dependence on methadone often goes hand in hand with the occurrence of *stigmatisation and discrimination* (Järvinen, 2008). Experiences of stigmatisation and discrimination are long-lasting (Link, Struening, Rahav, Phelan & Nuttbrock, 1997) and frequently hinder drug users in their daily functioning and the development of a positive identity (Simmonds & Coomber, 2009; Radcliffe & Stevens, 2008; Ahern, Stuber & Galea, 2007; Murphy & Irwin, 1992).
Feelings of dependence and stigmatisation can be mitigated by making individuals active participants and empowered decision-makers in their own treatment process (Holt, 2007; Ruefli & Rogers, 2004) and helping them to gain control over their lives, both of which are prominent components of a high QoL (Frain et al., 2009; Rosenfield, 1992). This can be advanced by providing methadone treatment through primary health care services, which is an effective way to minimise the social consequences of methadone treatment and improve opiate users' QoL (Harris et al., 2006; Fiellin et al., 2001; Schwartz, Brooner, Montoya, Currens & Hayes, 1999).

In general, opiate-dependent individuals consider methadone a *transitional phase* to tide them over during a certain period in their life (Potik, Adelson & Schreiber, 2007). The majority of participants in this study aim for an opiate-free life without methadone dependence, but given the chronic, relapsing nature of opiate dependence this is not a simple objective (Van den Brink & Haasen, 2006; Van den Brink, Goppel & van Ree, 2003). Harm reduction, and methadone treatment in particular, can be a vital link in the recovery process (McKeganey et al., 2004). Instead of placing harm reduction and abstinence-oriented approaches in opposition to each other, both approaches could be part of a continuum in order to enhance opiate-dependent individuals' QoL (from a long-term perspective) (McKeganey, 2005; McKeganey et al., 2004; Broekaert & Vanderplasschen, 2003). Nevertheless, for a number of participants, abstinence might not be realistic or even desirable (Magura & Rosenblum, 2001), and for those individuals substitution treatment can be a life-long aid in enhancing their QoL and gaining control over their drug use and their lives. Moreover, participants' stories reveal that getting clean is a prior condition for – rather than a direct component of – a high QoL (Granfield & Cloud, 2001).

6.4.1 Limitations

One of the frequently mentioned limitations of in-depth qualitative research is the subjective character of these methods. However, this subjectivity turns out to

be a large advantage in QoL studies, since it allows for the focus on individuals' own perspectives (Dale, 1995). Qualitative research is more likely to provide context-specific information about drug users' lives and to address the complexity of their life experiences (Neale et al., 2005; Fountain and Griffiths, 1999). Furthermore, exploratory, qualitative research methods create the possibility for participants to introduce themes that they find relevant without the bias of the researcher and apart from existing stereotypes (Neale et al., 2005). Diener and Suh (1997) demonstrated the complexity of the construct of QoL and encouraged research that measures QoL from different methodological and theoretical approaches. Nevertheless, the findings of this exploratory study may not be generalisable, nor can any causal relationships be specified. This study focusses on a specific group of opiate-dependent individuals, so caution is needed when generalising these results to other drug-using populations or to opiate-dependent individuals in general. Further qualitative research is advisable to explore the themes revealed in this paper and to expand our knowledge about the conceptualisation of QoL to other groups of substance users, both in and out of treatment.

6.4.2 Conclusion

From this qualitative study, it was possible to gain insight in the complex nature of components that contribute to opiate-dependent individuals' QoL and the ambivalent effects of methadone on those components. Efforts should be made to limit the negative consequences (e.g. stigmatisation) of methadone treatment on opiate-individuals' QoL, as well as to increase its benefits in opiate-dependent individuals' daily life (e.g. by making individuals active participants in their own treatment process). The findings of this study highlight the fundamental importance of social integration, psychological well-being, independence (obtaining control and mastery of one's life) and purposeful living in achieving a high QoL. Opiate-dependent individuals must be supported in their daily lives by means of practical, social and environmental support, alongside pharmacological treatment, in order to achieve a general feeling of satisfaction. Several of the themes that were relevant according to individuals' own perspectives (e.g. independence, meaningful life) are seldom introduced into QoL research and are miles away from current treatment goals. Finally, it is important to employ a user-driven approach to gain insight into the aspects that determine individuals' QoL, and to empower opiate-dependent individuals as active agents in their own progress toward a 'good life'.

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Chapter 7

General discussion

Abstract

In this final chapter, we summarise the main findings of this dissertation and highlight the most remarkable conclusions of the four studies. We further discuss the implications of this dissertation for clinical practice with opiate-dependent individuals and present some concrete recommendations in order to enhance the QoL of these individuals. Finally, we address the overall limitations of this dissertation and provide some guidelines for future QoL research in this field.

7.1 Introduction

The main objective of this dissertation was to explore the concept of QoL in substance abuse research, in particular with opiate-dependent individuals, and to investigate its usefulness for clinical practice. Great emphasis was placed on opiate-dependent individuals' own perspectives in order to gain insight in their current QoL, important aspects associated with QoL and the impact of methadone on their daily living situations. In a first study, attention was given to the conceptualisation of QoL by drug users, starting from their own personal view. In a second study a systematic review was made on available research on QoL of opiate-dependent individuals. Based on these first two studies, we set up the design and used instruments of a third, quantitative study on current QoL of opiate-dependent individuals and potential determinants of QoL. In this quantitative study, high importance is ascribed to aspects (potential determinants/protective factors and risk factors) that were connected with opiate-dependent individuals' QoL and that could be influenced in a positive way by clinical practice. In a fourth qualitative study, based on individuals' narratives, important components of QoL and the influence of methadone on these components are investigated. The main findings of these four studies are discussed in the following chapter. Furthermore, implications for clinical practice, study limitations and recommendations for further research are raised.

7.2 Main findings

7.2.1 Drug users' perspectives on QoL

Due to the limited attention to QoL in substance abuse research and the neglect of substance abusers' own perspectives, the goal of our first study was to define the concept of QoL, based on drug users own experiences. In this dissertation, QoL is approached as a *'sensitizing notion'*, based on an individual's personal feelings and experiences (Taylor & Bogdan, 1996). Consequently, our starting point and source of information were drug users' own opinions about the concept of QoL. We found that drug users perceived the concept QoL as a broad and multidimensional concept, not primarily associated with health (*Chapter 2)*. 'Social inclusion', 'self-determination' and 'personal relationships' were most frequently mentioned as important domains of QoL, illustrating the contextual character of the concept (De Maeyer, Vanderplasschen & Broekaert, 2009). We concluded that the theoretical framework of Schalock (1996), widely accepted in the field of disability studies, was also applicable among drug users. However, the interpretation and some of the restrictions experienced in the QoL-domains,

were specific for drug users' own social situation (e.g. not having a clean record). This study revealed important domains for drug users' QoL, which are not frequently included in substance abuse research, and demonstrated the usefulness and feasibility of involving drug users in substance abuse research.

7.2.2 Available evidence on QoL of opiate users

The second study, clearly demonstrated the large discrepancy between drug users' own perspectives about QoL (*Chapter 2)* and the current approach in QoL studies in substance abuse research, in particular among opiate-dependent individuals (*Chapter 3).* Our review of published studies on QoL of opiate-dependent individuals showed that QoL is often used as an umbrella term, covering concepts as health status, functional status and health-related quality of life. This inconsistent use of the concept QoL, results in a number of studies talking about the same 'concept', but actually measuring something completely different (De Maeyer, Vanderplasschen & Broekaert, 2010). In general, attention for QoL in substance abuse research is rather limited, and the focus in these studies is often restricted to HRQoL, a concept frequently confused and often equated with QoL (Rudolf & Watts, 2002). Furthermore, different types of instruments are used to measure QoL (e.g. generic/specific; global/domain-specific) (Zubaran & Foresti, 2009). These methodological and conceptual differences and the strong heterogeneity between studies hamper any comparison of results.

Nevertheless, evidence exists that the QoL of opiate-dependent individuals is low as compared with the general population, and most comparable with the QoL of individuals with psychiatric problems (Millson et al., 2004). A number of studies have found positive effects of substitution treatment on QoL, but these are mainly limited to the first months of treatment, while studies looking at the effects of substitution treatment on a long-term perspective are almost non-existent (Hser, 2007; Giacomuzzi, Ertl, Kemmler, Riemer & Vigl, 2005). Insufficient evidence is available about factors that influence the QoL of opiate-dependent individuals. Moreover, studies investigating the possible impact of variables on QoL by use of a multivariate design are lacking (De Maeyer et al., 2010).

The results of this review demonstrate the lack of research on the broad concept of QoL in opiate-dependent individuals, starting from a holistic approach, and the high prevalence of health-related quality of life studies in this field. Furthermore, this study illustrates the limited use of specific instruments to measure the QoL of opiate-dependent individuals. Therefore, we conclude there is a need for further research on QoL of opiate-dependent individuals, with special attention to their specific living conditions.

7.2.3 Characteristics of the sample and current QoL of opiate-dependent individuals

Between March 2008 and August 2009, 159 individuals who started an outpatient methadone treatment in the region of Ghent between 1997 and 2002 were interviewed. The majority of the participants were male (74.8%) and the mean age of the sample was 36.6 years (SD = 7.5). The mean age of onset for heroin use was 21.4 years (SD = 5.6), with an average period of regular consumption of 10.8 years (SD = 6.7). The mean duration of methadone treatment was 7.6 years (SD = 4.4), and about three-quarters of our sample was currently still in methadone treatment (*Chapter 4 & 5)*. This study shows that the majority of opiate-dependent individuals who started methadone treatment at least five years ago, are still in contact with treatment services, again illustrating the need to assess the long-term outcomes of substitution treatment. These findings demonstrate the chronic character of opiate dependence, which requires a continuing care approach (McLellan, 2002).
Furthermore, the majority of the participants reported problems in various life domains, besides substance abuse problems (e.g. employment, financial, legal, family and psychological problems). For instance, 87.9% of the sample experienced psychological complaints in the week prior to the interview on at least one subscale of the Brief Symptom Inventory (Derogatis & Melisaratos, 1983). These results illustrate the multiple and long-term needs of this specific group and confirm the hypothesis of negative scores on socially desirable outcomes (e.g. employment, debts) in long-term opiate-dependent individuals.

The *current QoL* of our sample was measured starting from a domain-specific, bottom-up approach (*Chapter 4)* (Wu & Yao, 2007). This approach resulted in divergent outcomes for the different QoL-domains. We found that low scores in one QoL-domain did not necessary imply low scores on another domain, illustrating the need to assess QoL in a multidimensional way. Another important finding of this study is that five to ten years after starting methadone treatment opiate-dependent individuals are still experiencing low QoL-scores on a number of domains (e.g. finances, family relations). Even of the group of participants who were no longer in treatment (25.8%) and who showed 'low' levels of recent heroin use (25.0%), a remarkable percentage reported unsatisfying QoL-scores on various domains (e.g. family problems, leisure and social participation). This might illustrate the long-term negative consequences of an opiate-dependent life style (even after experiencing positive treatment outcomes) (McLellan, Lewis, O'Brien & Kleber, 2000). Furthermore, this is one of the few studies that gives attention to the aspect of life meaning in QoL research on opiate-dependent

individuals (and drug users in general), measured by the Life Regard Index (Debats, Vanderlubbe & Wezeman, 1993). Consequently, an equally important finding of this study is that individuals reported high scores on the domain 'framework', illustrating they can envision their life having some meaningful perspective, while the rather large group with low scores on the domain 'fulfilment' (31.4%) illustrates the difficulties opiate-dependent individuals experience in actually fulfilling their life goals. These findings are at odds with the often existing assumption that opiate-users are not interested in the future and are only focused on continuing their drug use and suggest the importance of including aspects as life meaning in further QoL research (Ruefli & Rogers, 2004). The results of this study illustrate the usefulness of the QoL-concept in clinical practice to offer a total picture of an individual's living situation and the impact of their drug use on various life areas.

7.2.4 Determinants of opiate-dependent individuals' QoL

Due to the limited and inconsistent findings on determinants of QoL (De Maeyer et al., 2010), part of our quantitative study focused on the impact of demographic, psychosocial, drug- and health-related determinants of QoL. We started by looking at determinants of total QoL and then broadened our scope to the existence of possible domain-specific determinants of QoL, with attention for the multidimensional character of the concept and possible variation between QoL-domains.

One of the most remarkable and striking findings of this study on determinants of QoL is the absence of a direct effect of any of the drug-related variables on QoL (*Chapter 4 & 5)* (Bizzarri et al., 2005). Neither in the bivariate analyses (except for 'finances'), nor in the multivariate regression analyses, a direct effect of drug-related variables on QoL (both total and domain-specific) was retrieved, illustrating the limited direct influence of severity of drug problems on opiate-dependent individuals' current QoL (De Maeyer et al., in press). Few studies have investigated whether indirect effects of drug use on QoL could be retrieved. Given the complex nature of the concept of QoL, the high rates of current heroin use (49.7%) in our sample and the fact that heroin use is often interwoven with a specific lifestyle, such research is of clinical importance and was therefore further examined in this study. By use of path-analyses, we found that the effect of current heroin use on QoL was mainly indirect and restricted to a specific number of QoL-domains. The indirect effects of current heroin use were mediated by psychosocial (e.g. structured daily activity) and treatment-related variables (e.g. methadone dose) rather than health-related variables.

Looking at direct determinants of QoL, we found that total QoL was mainly determined by psychological well-being (e.g. psychological distress) and a

number of psychosocial variables (e.g. having a good friend) (*Chapter 4)*, while mainly psychosocial and person-related variables, together with satisfaction with treatment were important domain-specific determinants of QoL (*Chapter 5*). The high prevalence of psychological distress in our sample (54.1%) and its strong correlation with total QoL, suggest a strong impact of psychological complaints on the daily life of opiate-dependent individuals (Carpentier et al., 2009).
Furthermore, health-related variables only correlated with the domains 'health' and 'safety', and even the most important determinants of these domains were not health-related. The results of this study suggest that QoL of opiate-dependent individuals is mainly determined by psychosocial and psychological concepts (e.g. self-esteem), with a limited impact of variables related with a person's physical health (e.g. chronic medical complaints). Some evidence was found that, among others, having a structured daily activity, having an intimate relationship, employment, satisfaction with treatment and being able to fulfil life goals, were important protective factors associated with higher QoL-scores on various domains. The inability to change one's living situation was an explicit risk factor for a number of QoL-domains, as well as total QoL, while current heroin use was a rather indirect risk factor for QoL, given its negative correlations with a number of psychosocial variables.
The findings of our study once again confirmed the multidimensional character of QoL (also demonstrated in the study on current QoL) (Pitkänen, Hätönen, Kuosmanen & Välimäki, 2009). None of the QoL-domains was determined by the same compilation of variables, illustrating the specificity of each domain. This was also shown by the indirect effect of heroin use on QoL, which was only retrieved for half of the QoL-domains, excluding the domain 'health' (*Chapter 5)*. This finding suggests that heroin use is more decisive in some domains of QoL than in others. These data provide us with useful information, which can be transformed in a number of clinical interventions to improve opiate-dependent individuals' QoL (cf. infra).

7.2.5 Components of a good QoL and the impact of methadone on these components

To explore important components of a good QoL and the impact of methadone on these components, 25 participants were interviewed a second time as part of a qualitative study, starting from their own narratives. This study revealed five main themes, mentioned by the participants as important components of a good QoL: having social relationships, psychological well-being, having an occupation, being independent and having a meaningful life. As demonstrated in our review study (*Chapter 3)*, a number of these themes (e.g. being independent)

are seldom assessed in QoL research on opiate-dependent individuals (De Maeyer et al., 2010). Just as in our quantitative study on current QoL (*Chapter 4*), the importance of life meaning was highlighted in individuals' stories about a good QoL. Furthermore, some factors that were essential for a good QoL raised in the qualitative interviews (e.g. psychological well-being, having an occupation), were also retrieved as important determinants of QoL in our quantitative study (*Chapter* 5) (De Maeyer et al., in press). Most participants expressed the necessity to become clean of illegal opiates for having a good QoL, but only as a facilitator in order to achieve some of the important components of QoL, while quitting their opiate use alone, was not a direct component of a good QoL. An important finding of this study, is that it clearly illustrates the holistic character of the concept QoL (Schalock et al., 2002), which was characterized by a mutual connection between the different themes. The components that were characteristic for opiate-dependent individuals' period with the highest QoL after starting methadone treatment, had at first sight, a generic character (Diener & Ryan, 2009). Still, the interpretation of the themes and subthemes was often influenced by a number of obstacles or daily life experiences of opiate users as a result of their 'drug using life style' (e.g. replacement for their drug use). Nevertheless, opiate-dependent individuals aim for the same things in life as the general population, and express a strong desire to 'normalcy'.

This study further highlights the ambivalent influence of methadone on these important aspects of the good life for opiate-dependent individuals. A remarkable finding of this study is how something commonly perceived as 'a good', can also be 'a bad' when looking at it from a different perspective. Methadone was perceived as a transitional phase (in their life) by the majority of participants, which helped them by creating the necessary space and time needed to obtain some of the important components of a good QoL. On the other hand, methadone also turned out to have a negative impact on opiate-dependent individuals' QoL, given the social and practical consequences associated with following methadone treatment (Holt, 2007). Feelings of dependence and stigmatisation often jeopardise opiate-dependent individuals' overall QoL (Ahern, Stuber & Galea, 2007), and as a result, most participants associate a good QoL with being methadone-free and being independent of any substance. This study provides insight in both the supportive and disturbing 'side effects' of methadone on opiate-dependent individuals' QoL and offers in-depth qualitative data, allowing for an advanced interpretation of our quantitative study findings and further implications for clinical practice.

7.3 Clinical implications

This dissertation does not focus on the effectiveness and/or necessity of providing methadone treatment for opiate-dependent individuals (which has extensively been demonstrated in previous studies), but our aim was to investigate if and how methadone treatment can contribute to and/or negatively affect the improvement of opiate-dependent individuals' QoL. Furthermore, we investigated how the concept QoL can have a more prominent place in the treatment and support of opiate-dependent individuals.

7.3.1 Time for a shift in focus: where do we come from and where do we want to go?

Starting from the idea that opiate dependence is a chronic disease, comparable with other chronic illnesses (e.g. diabetes), clinical practice should be based on an integration of different interventions. Rather than starting from universal treatment objectives, this integration of interventions should reflect clients' needs at that specific time (Broekaert, 2009; Van den Brink & Haasen, 2006; McLellan, 2002). Recently, the recognition that addiction is a chronic disorder and – consequently – requires a continuing care approach, resulted in a growing attention to QoL in substance abuse research. Nevertheless, this rather limited and late attention to QoL in substance abuse research contrasts sharply with studies on other chronic illnesses, such as cancer, where QoL has a prominent place in treatment. Attention to QoL goes hand in hand with an upcoming interest in the consumer perspective, which is often lacking in substance abuse treatment, with its preponderant influence of the perspective of service providers (Ruefli & Rogers, 2004; McKeganey et al, 2004). If enhancing opiate-dependent individuals' QoL is one of our priorities in clinical practice, it will be inevitable to make a shift in focus to more person-centred outcomes, including QoL. Until today, substance abuse research and unfortunately also clinical practice have been characterised by an almost unique focus on objective and socially desirable outcomes (Fisher, Rehm, Kim & Kirst, 2005; Barnett & Hui, 2000). As a result, limited attention is given to how opiate-dependent individuals manage to live their life and how they perceive this. Nevertheless, information on the impact of treatment and disease on the daily life of individuals suffering from chronic illnesses is often much more revealing than hard outcome measures or information on their functional status, including symptom reduction (Wiklund, 2004).

The majority of the organisations providing care to opiate users presume that improvement of QoL will be a direct result of their treatment services, although

their focus is rather on socially desirable outcomes and the direct consequences of drug use, instead of the enhancement of their clients' QoL (Frisch, 1998). This utilitarian perspective is not appropriate if outcome measures and evaluation criteria want to emphasise on person-centred treatment, starting from client's experiences (Fischer et al., 2005). An important question is: What is the main focus in treatment for opiate-dependent individuals? Does clinical practice start from a rather populist view, determined by policy aims and mainly based on the restriction of nuisance and reduction of crime, or is our starting point the well-being of our client (McKeganey, 2005)? The gains of methadone substitution treatment are often unilateral defined to drug and harm-related outcomes, with limited attention to the broader lifestyle aspect of opiate-dependent individuals (Best et al., 1998). However, harm reduction, with methadone substitution treatment as one of the main pillars, is often described as a pragmatic way of dealing with drug problems, based on clients' needs (Denning, 2001). Nevertheless, not seldom clients are confronted with a restricted offer of services, which starts from a certain philosophy with limited attention for the client's own expectations about treatment (Järvinen, 2008). An important implication for clinical practice is that when their primary goal is to improve individuals' well-being based on clients' needs, it will be more important to start from client's perspective, instead of society as a whole. According to these findings, QoL should be action-oriented and become part of treatment evaluation as a valuable outcome measure, instead of a vague concept, only briefly mentioned in the mission statement of an organisation (Katschnig, 2006; Mezzich & Schmolke, 1999).

Even more important for clinical practice, is to include QoL in the assessment and treatment planning of clients' needs and the further monitoring of their treatment process (Frost et al., 2007; Katschnig, 2006; van den Bos & Triemstra, 1999). One of the intentions of a harm reduction approach is to involve clients in determining their own goal setting (Ruefli & Rogers, 2004); from this perspective admitting QoL in assessment and treatment planning of opiate-dependent individuals is indispensable. Integrating QoL in clinical practice will improve the communication between clinicians and clients and will result in shared decision making, leading to the enhancement of control and active involvement of clients (Frost et al., 2007; Mezzich & Schmolke, 1999). Effectiveness of treatment will improve when outcomes are based on clients' needs and their definition of progress rather than on goals determined by clinicians (Lasalvia et al. 2005; Ruefli & Rogers, 2004). Therefore, we suggest the use of a validated QoL-instrument, such as the Lancashire Quality of Life Profile, to support clinical practitioners in their daily practice to work with an abstract concept as QoL. Such a domain-specific instrument will provide detailed information on different areas of a client's life (Wu & Yao, 2007), and reveal

clients' needs starting from a holistic approach, with attention to both, problem areas and strengths in the individual's life (Frost et al., 2007; van den Bos & Triemstra, 1999). By use of QoL-measures, the focus is on aspects that can be improved and positive aspects that can be prolonged. Our goal in clinical practice will be to fulfil an individual's needs and expectations, in order to lead a meaningful life, rather than the absence of symptoms and illness-related problems (Schalock et al., 2002). These implications will result in a shift of paradigm from a rather negative, problem and pathology-oriented approach of treatment (e.g. Addiction Severity Index), to a strength-based approach, with attention to empowerment and control of opiate-dependent individuals (both related to a good QoL) (Mezzich & Schmolke, 1999). This strong, emancipatory approach, with a focus on individuals' strengths and capacities to enhance their well-being is also retrieved in the principles of positive psychology, that starts from a fortigenic perspective (Naidoo, 2006). Unfortunately, until today, consumer empowerment is not seen as a priority by many health professionals, reasoning that clients are not waiting to become involved as actors in their own goal-setting and process of care and support (Segal, 1998). Nevertheless, research has demonstrated that empowerment of clients (by determining their own needs) contributes to their rehabilitation outcomes and their general health status (Frain, Bishop & Tschopp, 2009; Segal, 1998).

7.3.2 Improving QoL: where do we start?!

The need for an integrated and comprehensive treatment approach starting from a continuing care perspective

Our study revealed that drug users' QoL is not primarily associated with health or health-related aspects, but is strongly related with aspects such as social inclusion and self-determination (De Maeyer et al., 2009). Comparable results were found with clients in mental health care, where most areas important for QoL were not illness-related (Pitkänen et al., 2009). Research has demonstrated that clients' perspectives on QoL are often in contrast with care givers' definition about the concept (Angermeyer, Holzinger, Kilian & Matschinger, 2001), illustrating the importance to have attention to drug users' own perspectives.

The findings of our first study imply that if we want to enhance opiate-dependent individuals' QoL in clinical practice, it will be inevitable to give attention to various domains in clients' life and broaden our outcome measures. A unique focus on drug-related issues and the physical health of clients will not result in improved QoL scores. However, these aspects will have a direct influence on individuals' health status or HRQoL and might as a result have an indirect effect

on individuals' QoL. Concepts as 'self-determination', 'social relationships' and 'social inclusion' are seldom included as direct treatment goals, although they appear to have a significant impact on experiencing a satisfying life. Moreover, targeting improvement of QoL in different life domains may indirectly result in the reduction of illness-related symptoms (Frisch, 1998). For instance, enhancing opiate-dependent individuals' social integration will result in higher QoL scores and may as well influence opiate users' drug-related behaviour, making it an indispensable treatment goal from both an individual and a societal perspective. Furthermore, improving QoL of opiate-dependent individuals can have a positive impact on preventing relapse, knowing that more is needed than quitting drug use, to recover from drug dependence and maintain a drug free life style (Laudet, 2007; Moos, 1994). Furthermore, opiate-dependent individuals often experience a lot of barriers, such as stigma and discrimination, when trying to build out a new social network and become part of the community again, so attention is needed to the social difficulties opiate-dependent individuals are facing (Ahern et al., 2007; Murphy & Irwin, 1992). As a result, a comprehensive and holistic treatment approach is essential if clinical practice wants to play an important role in improving clients' QoL (Vanagas, Padaiga & Bagdonas, 2006; Schalock & Verdugo Alonso, 2002).

Besides the multidimensional character of QoL, the need for an integrated and comprehensive treatment approach is also illustrated by the multiple needs of opiate-dependent individuals in different areas of life (McLellan et al., 2000). Substance abusers often experience additional problems such as homelessness and psychological problems, hindering their access to substance abuse services, which are often focused on drug users, with limited or no additional problems (Vanderplasschen, Rapp, Wolf & Broekaert, 2004). Nevertheless, the results of this study demonstrate that such a group is almost non-existent, and problems in different areas of life are the rule rather than the exception. Five to ten years after starting methadone treatment opiate-dependent individuals were still confronted with a number of problems on different life domains. Remarkable is that these problems were less explicit for the domain 'health', but individuals rather experienced feelings of dissatisfaction regarding their financial and family situation. These findings might illustrate the effectiveness of methadone treatment in improving opiate-dependent individuals' health-related problems, resulting in higher satisfaction scores on this life domain.

Another important implication that can be derived from these findings is the need for a continuing care perspective, given the dissatisfaction on different life domains many years after starting methadone treatment. The chronic character of opiate dependence also results in a growing group of older opiate users, with specific and changing needs for support (Lofwall, Brooner, Bigelow, Kindbom & Strain, 2005). Moreover, a comprehensive and continuous approach is

required in substance abuse treatment in order to deal adequately with opiate users' multiple and often long-term problems, and not reducing these problems to drug use. Case management has been demonstrated as a successful intervention to deal with individuals with multiple needs and to improve the coordination and continuity of care, starting from a client-centred approach (Vanderplasschen et al., 2004). More specifically, strengths-based case management that builds on a person's strengths and abilities, is a very useful alternative for the dominant pathology-oriented practice in substance abuse services, and perfectly links with the QoL-paradigm by stimulating clients' involvement and empowerment (Brun & Rapp, 2001).

Psychosocial support: the missing ingredient!

In our third study, a number of direct associations have been found between psychosocial, person- and treatment-related variables and opiate-dependent individuals' QoL. Notably, no direct association was found between any of the drug-related variables and QoL. As a result, one of the most important implications of this study is that besides the pharmacological support, there is an urgent need to broaden the care and support for opiate-dependent individuals by providing them with psychosocial support. Psychosocial services are seen as a vital component of support for opiate-dependent individuals (as well during as after methadone treatment). In this study only 42.6% of the sample received psychosocial treatment during their last or current treatment. Looking at the frequency of this psychosocial treatment, we saw that 45.0% of this group had irregular contacts with a social worker (less than monthly). One of the most important findings regarding psychosocial support is that this support is not systematically offered and is only available for individuals that explicitly ask for it. At present, psychosocial support is one of the pillars of methadone maintenance treatment, but in everyday reality the availability of psychosocial support is rather limited, partially caused by shortage of staff and a restricted budget. This is mainly explained by the fact that in Belgium, the majority of the public funding for drug policy still relates to law enforcement, although there is a primordial focus on rehabilitation and harm reduction, and repression is seen as an ultimate remedy (Lamkaddem & Roelands, 2010). It is important to find a structural solution for the lack of staff in methadone maintenance treatment for intensive psychosocial support. Besides additional staff, another option could be a close cooperation with external services offering the needed psychosocial support (Trautmann et al., 2007). Nevertheless, if our goal is to meet the individual needs of our clients and enhance their QoL, a combination of medical and psychosocial services is a must (WHO, 2009; Amato et al., 2004; McLellan, Arndt, Metzger, Woody & O'Brien, 1993). Psychosocial services can support

clients with daily problems regarding unemployment, lack of structured daily activities, housing problems, etc. More psychological aspects such as lack of meaningful perspectives in life and low self-esteem can be handled by providing psychotherapeutic support to clients. Therefore, we suggest the use of an integrated set of methods (e.g. psychotherapy, motivational interviewing, family therapy) in clinical practice, depending on clients' individual situation and needs (Broekaert, 2009; Tatarsky, 2003). A limited number of individuals might not express the needs for psychosocial support, perhaps because they have a strong, informal social network that supports them in their daily life or they have the feeling they can manage on their own. Although this is rather exceptional, psychosocial treatment should not be mandatory, and has to start from a user-driven approach (Fischer, Chin, Kuo, Kirst & Vlahov, 2002). Outreaching can be a successful way of approaching people in their daily living situation and making contact, which can make psychosocial treatment more accessible and result in 'spontaneous' counselling (van Doorn, van Etten & Gademan, 2008).
Finally, the long-lasting implications of opiate dependence, also urge for the importance of continuing care and after care in different life domains (e.g. social rehabilitation), even when individuals are no longer dependent on illegal opiates and have successfully finished their methadone treatment (Vanderplasschen, Bloor & McKeganey, 2010).

7.3.3 Off we go: crucial aspects for supporting QoL among opiate-dependent individuals

To conclude, we offer a number of specific recommendations to improve opiate-dependent individuals' QoL in clinical practice. By investigating the impact of a number of variables on opiate-dependent individuals' QoL, one of our goals was to translate our research data on QoL into meaningful clinical practice.

Attention to psychological problems

Due to the high amount of psychological distress in our sample (54.1%) and the negative association of psychological problems with QoL, early identification of psychological problems and their potential impact on individuals' daily life should be a standard aspect in clinical practice for opiate-dependent individuals. Research has demonstrated that opiate-dependent individuals are very vulnerable to psychological problems (e.g. Carpentier et al., 2009; Rodriguez-Llera et al., 2006), affecting their QoL in a negative way (e.g. Bizzarri et al., 2005). Furthermore, opiate users who needed treatment for psychological complaints, also experienced more problems in other life domains (e.g. finances,

employment) compared with the group without psychological complaints (Meulenbeek, 2000), showing the potential risk of psychological distress on individuals' QoL. Attention should also be given to the high rate of current benzodiazepine use in our sample (57.2%), due to the ongoing debate of the (un)appropriate use of benzodiazepines and antidepressants for individuals with both substance use disorders and psychological problems (Holt, 2007; Brunette, Noordsy, Xie & Drake, 2003). We strongly advise that besides the medical support, psychotherapeutic approaches are provided to manage psychological problems such as depression and anxiety.

Social support and social inclusion

If treatment wants to enhance the QoL of its clients, it will be important to realise that opiate dependence is not an isolated problem of a unique individual, apart from the social context in which they live (Scherbaum & Specka, 2008). Attention should be given to the environmental and contextual components that interact with an individual's QoL (e.g. lack of supportive network, loss of identity) (Schalock et al., 2002). The positive effects of a supportive social network have been frequently demonstrated (Flynn, Joe, Broome, Simpson & Brown, 2003; Granfield & Cloud, 2001), but unfortunately, our qualitative studies revealed that this is one of the aspects opiate-dependent individuals are often missing or have lost in the past years. A harm reduction approach tries to support the social inclusion of clients by supporting them in their natural environment (Denning, 2001), but not seldom this natural environment only consists of other drug users, and support provided by their natural network is limited. Furthermore, experienced feelings of shame and stigmatisation (e.g. based on negative stereotypes) can set a person apart from others and negatively affect opiate users' social integration as a whole and should therefore not be underestimated (Simmonds & Coomber, 2009). According to our findings, research suggests that it is mainly the social consequences of a chronic disease and the impact on individuals' daily living, that affect their QoL, rather than the severity of the illness itself (symptom-related) (Kilian, Matschinger & Angermeyer, 2001), again urging for the development of a social capital, broader than a drug-using community, with attention to aspects as stigma and discrimination. Strengthening clients' social capital should be a priority in treatment, in order to expand a person's informal network and enlarge the possibilities of self-help. Family therapy can be a very productive component of treatment to fulfil this goal (Heinz, Witkiewitz, Epstein & Preston, 2009).

Occupation

A number of studies have already demonstrated the importance of work and having a meaningful daily activity for QoL (Ay-Woan, Sarah, Lylnn, Tsyr-Jang, & Ping-Chuan, 2006; Jarbin & Hansson, 2004; Huxley, Evans, Burns, Fahy & Green, 2001). Both the findings of our quantitative and our qualitative study showed the importance of a structured daily activity and/or employment on opiate-dependent individuals' QoL. These findings illustrate the need for vocational therapy/rehabilitation in treatment services for opiate-dependent individuals to enhance their QoL. Social workers also need to be sensitive for the restrictions of following a methadone treatment (e.g. daily collection of methadone) and current drug use on aspects as employment, making it desirable to integrate vocational therapy in their methadone maintenance treatment (Coviello, Zanis, Wesnoski & Domis, 2009). Our qualitative data also highlighted the positive impact of having an occupation on aspects as self-worth, increased feelings of independence and social inclusion. Therefore, vocational therapy is a useful and attainable clinical intervention to enhance opiate-dependent individuals' overall QoL. However, for some individuals it might be important to support them first with a number of problems, such as health problems, housing issues and stabilizing their drug use, before employment is a realistic proposition. Attention for long-term barriers (e.g. no clean record, lack of confidence and skills) that hinder chronic drug users in participating in the labour market is needed, before they can be engaged in employment-related activities (training, voluntary work) (Kemp & Neale, 2005).

Housing

Studies in mental health have demonstrated the stabilising impact of proper housing on the every day life of individuals and its positive impact on health (Kyle & Dunn, 2008; Bebout, Drake, Xie, McHugo & Harris, 1997). Aspects of housing are not only connected with the domain living situation, but have an impact on other life domains as well (Brunt & Hansson, 2004). The high percentage of respondents in our sample who were in the inability to change their living situation (74.0%) – in contrast with the limited number of homeless individuals (8.2%) – demonstrates that providing shelter alone is not enough. Other aspects such as independence, privacy and a safe neighbourhood need more attention, knowing that there is a positive association between housing preferences and the QoL of individuals with both psychiatric and substance abuse problems (Kyle & Dunn, 2008; O'Connell, Rosenheck, Kasprow & Frisman, 2006). Furthermore, concerns regarding their housing situation can hinder opiate-dependent individuals by interfering with access to and continuity

of treatment (Gray & Fraser, 2005). Consequently, the results of this study demonstrate that housing is not a side-issue, but one of the priorities in treatment to enhance QoL.
Comparable to the issue on occupation, the aspect of housing will be influenced by a societal dimension (cf. infra). The power of clinical practice on aspects as a tight labour market and the availability and affordability of suitable accommodation is limited, notwithstanding the offered support on these aspects (Kilian & Angermeyer, 1999).

Life meaning

Although the lack of attention to aspects as life meaning and future perspectives in substance abuse research, both aspects are important components of QoL. The fact that the majority of the participants could envision their life as having some meaningful perspective is a hopeful and promising finding, because of its positive association with life satisfaction and its possibility to bring structure to an individual's life. Still, the subjective character of life meaning hinders its integration in clinical practice (Debats, Drost & Hansen, 1995). Nevertheless, clients' personal future perspectives and hopes will be the ideal starting point for strength-based support in treatment, based on an individual's own needs (Calman, 1984). Given the high importance of purposeful living in achieving a good QoL, efforts should be made to introduce the concept of life meaning in treatment of opiate-dependent individuals. The qualitative stories revealed that even when individuals have managed to put their life back on the rails after many years, finding a purpose in life again and often a replacement for their drug use, is one of the hardest things to achieve. Psychotherapeutic methods might be suitable to address these difficulties and help clients in their search for meaningfulness. Informal social networks (e.g. partner, children) might as well contribute to this feeling of purposeful living and support individuals in their search for a "new reason to live". Once again, it will be necessary to support opiate-dependent individuals in this process, because they will frequently be hindered by factors disturbing the realisation of their future goals (e.g. stigma, lack of clean record).

7.3.4 Limiting the negative consequences of methadone and expanding the benefits

The results of our study have demonstrated the strong ambivalence of opiate-dependent individuals' ideas about the impact of methadone treatment on their QoL. The findings of our literature review have shown that methadone treatment can be effective in improving the QoL of individuals, especially during the first months in treatment (when clients stabilise after a period of crisis). The qualitative interviews expanded this information by demonstrating the positive effects of methadone, among others, on withdrawal effects, controlling clients' opiate use and being able to function normally. Methadone substitution treatment can be a successful support for opiate-dependent individuals and contributes to a good QoL by creating the necessary space to deal with a number of difficulties. Nonetheless, only taking methadone, without further action might result in an improved health status, but will have a limited impact on individuals' broader QoL. Furthermore, one of the implications of this study is that the social consequences of methadone on individuals' QoL (e.g. stigmatisation, dependence) should not be underestimated (Anstice, Strike & Brands, 2009; Rosenfield, 1997). Moreover, these social consequences might make individuals reluctant of using the offered services and becoming visible as a person with a 'drug problem' (Simmonds & Coomber, 2009). It should at all times be avoided that methadone treatment becomes an overpowering factor in an individual's life. Therefore, attention should be given in clinical practice to the restrictions of methadone treatment on individuals' daily life (Holt, 2007). Making clients active decision makers in their own treatment process (e.g. pro-active provision of information, involvement in decision-making on medication and goal setting) will have a positive impact on their feelings of independence and might as well result in an enhancement of their QoL (Ruefli & Rogers, 2004). Enhancing clients' empowerment is also known as a successful 'tool' to counter experiences of stigma (Lundberg, Hansson, Wentz & Björkman, 2008). Furthermore, stigma and discrimination might be diminished by supplying methadone through primary health care (Harris et al., 2006; Fiellin et al., 2001) and local pharmacies with respect for the privacy of the client. By doing so, there will be little contact with other drug users which will be more convenient for a number of opiate-dependent individuals (Simmonds & Coomber, 2009). Finally, training of staff, social workers and pharmacies about important aspects of opiate dependence and countering a number of stereotypes will have a positive impact on the well-being of opiate-dependent individuals and society as a whole (Simmonds & Coomber, 2009).

"Nothing defines the quality of life in a community more clearly than people who regard themselves, or whom the consensus chooses to regard, as mentally unwell."
Renata Adler (1938 -)

7.3.5 Improving QoL: a challenge to society as a whole

An often heard criticism on the integration of QoL in daily practice is the high costs it involves in providing support to individuals with chronic illnesses (e.g. multidisciplinary team, long-term support). Nonetheless, on a long-term perspective people who achieve a higher QoL, will have a bigger chance of becoming a productive member of society again, illustrating the cost-effectiveness of this paradigm (Awad & Voruganti, 2000). Finally, we would like to emphasise that besides the relevance of QoL for clinical practice, it is first of all an ethical duty of society to take care of individuals who are ill, disabled or disadvantaged, and support them in achieving a satisfying QoL (Corring & Cook, 2007; Kilian et al., 2001; Kilian & Angermeyer, 1999). Clinical practice can only influence a restricted number of factors that can contribute to a better QoL, but a number of factors that affect the QoL of people living in socially marginalised situations (e.g. community stigma) should be dealt with by the broader society (e.g. mass media, policy) (Schalock et al., 2002; Kilian & Angermeyer, 1999). This societal component of QoL is strongly connected with the Universal Declaration of Human Rights (1948), which, among others, contains the right of care and support and a certain standard of QoL for all people. The centralisation of human rights was highlighted in the last action plan on drugs of the European Union (2008), and special attention was given to the social exclusion of drug users (EMCDDA, 2009).
In general, low employment rates and an ageing population result in a growing attention to QoL as a direct policy goal in the European Union (e.g. the development of an interactive database on QoL in Europe – EurLIFE). The latest results of the European Quality of Life Survey (EQLS) (2007) illustrate the negative influence of objective aspects as deprivation, unemployment and poor health on life satisfaction in all countries of the European Union. Furthermore, social support and the quality of public services were strongly related with individuals' life satisfaction (Watson, Pichler & Wallace, 2010). Therefore, the impact of choices based on economic and political grounds on individuals' QoL should not be underestimated (e.g. the expenditure of funding on repression strategies instead of focussing on reintegration and empowerment of individuals) and attention to the broader environmental factors influencing individuals' QoL is needed.

7.4 Orthopedagogical implications

In this paragraph, the orthopedagogical implications of this study are highlighted. As already demonstrated in the introduction of this dissertation, orthopedagogics is an integrative, scientific discipline, with a practice-oriented character directed towards action (Broekaert, D'Oosterlinck, Van Hove & Bayliss, 2003). Because of its integrative and practice-oriented character, orthopedagogics differentiates itself from allied scientific disciplines such as psychology and psychiatry. Consequently, this specific orthopedagogical approach has serious implications for the way we *act* with human beings (in this case opiate-dependent individuals).

First of all, orthopedagogics is directed towards integration and practice. Striving for improvement and development of an individual in problematic living situations is the essence of our work as an orthopedagogue. QoL, as a subjective component is an essential part of this, and therefore inseparable from an individual's broader development (Broekaert, Autrique, Vanderplasschen & Colpaert, 2010). As a result, QoL is and should be an integrated part of our human orthopedagogical care. Given the fact that QoL is not an absolute condition, but a changeable, dynamic entity (Allison et al., 1997), improvement of an individual's QoL is possible and essential. QoL is part of the human existence, and from an orthopedagogical approach a satisfying QoL is a human right, that should be supported for all people (Broekaert et al., 2010).

Second, as a result of the integrative character of orthopedagogics, the core findings of this study cannot be considered apart from each other. Based on our orthopedagogical grounds, the organisation of care and support for opiate-dependent individuals should be based on a fruitful interaction of different treatment modalities. Therefore, the clinical implications of this study need to form an integrated entity, with attention to the different aspects, which complement each other, starting from a holistic perspective. However, when these different implications are approached apart from each other, without attention to their interdependence, this will not contribute to an orthopedagogical action. One single treatment system does not capture the complexity of the human existence, and from an orthopedagogical standpoint an integrated and comprehensive treatment approach is suggested, based on various treatment modalities, starting from a continuing support perspective (Broekaert & Vanderplasschen, 2003). Therefore, the mutual concurrence between different treatment modalities (in substance abuse research) should be counterbalanced, in order to improve individuals well-being based on an integration of services

tailored to their individual needs (McKeganey, 2005). Consequently, we strive for a combined and integrated action of medical, psychological and social aspects, in order to improve a person's living situation, of which QoL is an integral part.

Finally, starting from an orthopedagogical approach, the provision of methadone treatment should be part of the broader development of human mankind. Methadone is seen as a therapeutic agent, to improve the growth and development of a human being, rather than a substitute that prevents individuals from using drugs. The personal development, with QoL as an essential part of it, is the first matter of importance, not the reduction of drug use. The orthopedagogics passes no value judgement on the use of drugs in society. It is not the use of a substance that has a central position in the orthopedagogics, but the improvement of a person's well-being who uses this substance in a way that it negatively affects its QoL. As a result, a restricted focus to drug use and drug-related aspects is undesirable from an orthopedagogical view. Consequently, it will be necessary to integrate methadone with different interventions, such as psychosocial support, in order to improve an individual's personal development. From this perspective, methadone can be a useful aid and an important component in order to achieve an enhancement of opiate-dependent individuals' well-being.

This integration of methods and theories is also in line with the research design of this dissertation, which is based on a mixed methods approach, with extensive attention to the subjective perspective of an individual. Therefore, a specific orthopedagogical approach is not only important in our daily practice with individuals, but also in research, which is carried out in order to influence clinical practice and our acting in a positive way.

Concluding, we want to argue in favour of a striving for open-mindedness, starting from a variety of perspectives, in order to enhance an individual's QoL.

7.5 Methodological issues and limitations of the study

Although the most important methodological issues and limitations of each study have been discussed in the related chapters, we focus in this section on some overall methodological issues and limitations of this study.

7.5.1 Methodological constraints when measuring QoL

The conceptual inconsistency of the concept of QoL, results in some methodological issues when one wants to 'measure' the concept. In the following paragraph we want to put forward some methodological implications that play a role when measuring QoL (and choosing an appropriate instrument), based on our own experience and drug users' conceptualisation of QoL.

Defining the concept QoL and deciding what the goal of your research is (what you want to measure) are inevitable steps, before you can choose an appropriate QoL-instrument (Dijkers, 2007; Simeoni et al., 2000). In this study we chose to conceptualise QoL as a subjective concept, defined in terms of individuals' satisfaction with life, clearly demonstrating the difference with the concept HRQoL (Moons, Budts & De Geest, 2006). For use in substance abuse research and practice our findings illustrate the importance of using an instrument that respects the subjective character – starting from individuals' own experiences – and the multidimensionality of the concept QoL (Awad & Voruganti, 2000). Another condition is that the psychometric properties have been demonstrated in the specific target group.
One of the possible limitations for the use of QoL in clinical practice is its vague an rather abstract character, when QoL is measured as a unidimensional concept (top-down perspective), without attention to the heterogeneity and variation in different domains of QoL (Cummins, Lau & Stokes, 2004; Donaldson & Moinpour, 2002). Therefore, we suggest a bottom-up perspective by evaluating the QoL of an individual based on his/her satisfaction with various domains (Wu & Yao, 2007). This bottom-up perspective is very useful from a clinical point of view to work out individual treatment goals and detect changes in an individuals' life. Furthermore, it will also be advisable to have attention to the importance people attribute to different domains, since QoL is often lower in domains of high importance (Pitkänen et al., 2009) In our opinion, QoL can only be measured in a subjective way, because it is based on the personal expectations and values of an individual. Nonetheless, it might be interesting to investigate the connection between QoL and a number of objective 'indicators', which are

useful to discriminate between populations and can be strived for at policy level (Fakhoury & Priebe, 2002).
Another decision that has to be made, is the choice for a generic or specific QoL-instrument. The emerging themes of a good QoL for opiate-dependent individuals and the way in which drug users defined the concept QoL, illustrates that people dependent on drugs are first of all human beings, longing for the same things as other people (e.g. being part of it, feeling useful). As a result, one might question if these important aspects in life have anything to do with opiate dependence in specific, questioning the necessity to use specific instruments to measure the QoL of this target group. Nevertheless, the results of our study illustrated that the interpretation of certain components of QoL (e.g. dependence), possible affecting factors or restrictions of QoL (e.g. stigma) might be specific for a certain population. Therefore, we suggest the use of a domain-specific instrument of QoL, with attention to various domains that might be affected by opiate dependence.

7.5.2 Generalisability, representativeness and comparability of the findings

A first limitation of this dissertation was that our study was limited to the broad region of Ghent (East-Flanders), given its high concentration of services for drug users and the practical constraints of this study. This restricted region and contextual differences might limit the generalisation of our data to other regions (in Belgium), with possible different treatment populations.
Second, the specific group of opiate users included in this study (who started methadone at least five years ago in the region of Ghent), restricts the generalisability of our findings to the larger group of opiate users.
Furthermore, it is also unclear if our sample is fully representative for the total group of opiate-dependent individuals who started a methadone treatment at least five years ago in the region of Ghent, although the age and gender distribution was identical to that of persons following an outpatient methadone treatment in the region of Ghent, between 1997 and 2002 (Vanderplasschen, Colpaert, Lievens & Broekaert, 2003). However, a selection bias might have occurred, since the majority of our sample was still in contact with treatment by the time they participated in the study. This was partly compensated by the use of various media (e.g. flyers, local television and radio) and snowball sampling to recruit participants for the study.
A larger sample size would also have created the possibility to use more sophisticated and complex statistical techniques, to further investigate possible interconnectedness of our data (e.g. large path model, including all domains of

QoL). Nevertheless, this limitation was partly compensated by the use of a mixed method approach to improve construct validity (Fountain & Griffiths, 1999).
And finally, the comparability of our findings with international data on QoL is limited, given the strong heterogeneity (e.g. conceptualisation of QoL, used substances) in the restricted number of QoL-studies in substance abuse research and the variety of instruments used to measure QoL. Given the lack of general population norms for the Lancashire Quality of Life Profile, it is not possible to compare opiate-dependent individuals' QoL with that of the general population or a non-clinical control group.

7.5.3 Cross-sectional design of the study

The largest limitation of this study is its cross-sectional character. Due to the practical constraints of this study (e.g. lack of a central methadone register, no baseline assessment, limited time frame), no longitudinal study could be carried out. Consequently, causality could not be examined, since possible determinants and QoL were measured at the same time, so we can only speak about associations or correlations between certain variables and QoL. We have no information on the predictive value of our findings; for example, it is possible that better psychosocial circumstances result in improved QoL, but it is also possible that somebody who is experiencing a satisfying QoL, is more successful in performing social roles in society. Furthermore, determinants associated with QoL, may fluctuate over time, illustrating the need for longitudinal research (Hansson & Björkman, 2007).
As a result of the cross-sectional design of our quantitative study, it was not possible to investigate the effects of methadone treatment on individuals' current QoL and no predictions could be made on the possible improvements or deteriorations in QoL as a result of following methadone treatment. Until today, QoL is not included in assessment or outcome measures in substitution treatment in Ghent, so no information on individuals' former QoL could be gathered from medical or social files of the clients.

7.5.4 Restrictions of used instruments

Since there are no specific QoL-instruments available for use with substance abusers – except for the injection drug user quality of life scale, which can only be applied with injecting drug users – we decided to measure opiate-dependent individuals' QoL by use of the Lancashire Quality of Life Profile, a domain-specific QoL-instrument used in the broad field of mental health. This instrument

was most corresponding with the findings on drug users' definition of QoL from the focus groups and has been used in international studies with opiate-dependent individuals following substitution treatment (e.g. Giacomuzzi et al., 2005). Nevertheless, it is possible that some domains important for opiate-dependent individuals' QoL are not integrated or fully assessed. However, comparable findings on conceptualisation of QoL are found between people with substance abuse problems and people with other mental illnesses (cf. infra) (Corring & Cook, 2007).

All instruments (self-reported and semi-structured interviews), except for one (MANSA), were administered in a face to face interview with the client. This was done in order to avoid literacy problems and create a sense of trust between the researcher and the client, as a basis for the qualitative interviews. Still, this approach might have increased the chance for socially desirable answers. However, the Manchester short assessment for quality of life self-report (MANSA), a shortened version of the LQOLP, was completed by all participants as a self-report questionnaire, and these findings were highly consistent with the results of the LQOLP.

Finally, we decided to report feelings of psychological distress (based on the Brief Symptom Inventory) instead of the actual prevalence of psychiatric disorders, based on a standardised diagnostic instrument. So no information on the prevalence of effectively diagnosed psychiatric illnesses is available, nor was the connection with QoL investigated.

7.6 Recommendations for future research

While QoL has rarely been included as an important outcome and assessment measure in substance abuse research, our findings show the importance of incorporating QoL in future research. QoL can (1) provide us with important information on the impact of drug use and the effect of treatment on individuals' daily life, (2) improve the development of strategies to enhance individuals' wellbeing and (3) attain insight in individuals' personal future goals they are striving for. Furthermore, the results of this study force researchers and clinical practitioners to rethink the dominant health- and drug-related focus in substance abuse research and practice, and stress the importance of starting from a broad, holistic perspective with attention to different life domains and psychosocial and person-related aspects.

Several important issues remain, which should be addressed in future research.

First, longitudinal studies are needed to investigate the empirical evidence found in this study. The fact that QoL is a dynamic construct, which can change over time, illustrates the need for studies with a longitudinal design (Carr & Higginson, 2001; Allison, Locker & Feine, 1997). A longitudinal study design would provide us insight in the potential predictive values of determinants and the path models retrieved in this study. Furthermore, such longitudinal research would provide us with adequate information on the effectiveness of substitution treatment on individuals' QoL and how we can optimise treatment services, based on clients' needs. Although clients usually have been following substitution treatment for a long period of time (7.6 years on average in this study), existing studies measuring the effectiveness of substitution treatment on individuals' QoL are limited to short-term periods. Therefore, it will be important to make a shift in focus from short-term to more long-term QoL research in opiate-dependent individuals, given the chronic nature of drug problems and their need for long-term care and support (McLellan, 2002; O'Brien & McLellan, 1996). Moreover, further QoL research is needed on the potential of other forms of substitution treatment (e.g. buprenorphine, diacetylmorphine), in enhancing individuals QoL. Until today, attention is mostly given to the effect of methadone treatment on individuals' QoL (De Maeyer et al., 2010), but other substitutes, such as buprenorphine might have more positive effects on QoL, given its less intense withdrawal effects, its usefulness in primary care settings and its possibility of less-than-daily-dosing (Maremmani et al., 2008; Marsch, Bickel, Badger& Jacobs, 2005). In general, more research is needed on protective factors (e.g. resilience) that can influence the QoL of individuals suffering from chronic illnesses (e.g. HIV, depression), with attention to possible indirect effects, given the complex relationship between different determinants and mediators of QoL.

Second, the focus in QoL research (in substance abuse research) is mainly based on quantitative studies measuring individuals' QoL, where a growing number of QoL-measures is noticeable, but attention to the conceptual development of QoL is rather limited. Given the complex nature of the concept QoL and the difficulties with interpreting the concept based on quantitative data, there is need for more qualitative methods in QoL research. Quantitative measures can only capture part of the story, and will inevitable result in a simplification of a persons' QoL; therefore more explorative research strategies, such as qualitative approaches (e.g. participant observation), with attention to the phenomenology of QoL are recommended (Hendry & McVittie, 2004).

In line with this second recommendation, we strive for more emancipatory research, involving opiate-dependent individuals themselves, as equal decision makers, in the discussion on research design, development of instruments and used methods (Gilbert, 2004). This bottom-up approach would be very useful in order to develop a specific QoL-instrument for this target group, starting from opiate-dependent individuals' own experiences and meeting their expectations. In accordance with a growing need of empowerment of clients in clinical practice, we suggest to follow the same line in research, which will contribute to an enrichment of our research activities and increase opiate-dependent individuals' wellbeing (Coupland et al., 2005).

Fourth, concepts as empowerment, independence and life meaning are seldom incorporated in QoL measures, which are often limited to a number of highly measurable variables (e.g. employment). Nevertheless, the results of our qualitative studies and previous research in mental health care (Boevink, Wolf, van Nieuwenhuizen & Schene, 1995), have demonstrated that these concepts are significant components of QoL and should be included for a complete coverage of the concept. Up till now, specific QoL-instruments for opiate-dependent individuals are almost non-existent (Vanagas, Padaiga & Subata, 2004) and aspects that restrict opiate-dependent individuals' QoL (e.g. stigma, discrimination, dependence) are seldom included in QoL-measures currently used in substance abuse research. This illustrates the need to develop a specific QoL-measure with attention to the social consequences of opiate dependence and important themes that attribute to their satisfaction with life.

Furthermore, comparable findings were found on affecting factors (e.g. stigma, isolation) and important themes (e.g. independence) of QoL for people with disabilities, mental health problems and dependence on drugs (De Maeyer et al., 2009; Corring & Cook, 2007; Michalak, Yatham, Kolesar & Lam, 2006; Van Loon, 2001). Based on this finding, a fifth recommendation is to extend conceptual research on QoL to the 'group' of people living in socially marginal situations (e.g. individuals with mental illnesses, HIV, disabilities), who are at risk for being excluded from society. It would be challenging to investigate the possibility to develop a specific QoL-instrument for individuals who are excluded from the mainstream, especially knowing that social consequences of a chronic 'illness' have the largest impact on an individual's QoL (Kilian et al., 2001). We suggest starting from exploratory qualitative research, to gain insight in the possibilities of this proposed track.

Finally, one of the most remarkable findings of this dissertation was the fact that opiate users were seldom asked about what *they* saw as important aspects in their life and their personal goals and hopes for the future. In addition, they were seldom asked about things that went well in their life, starting from a focus on strengths, instead of a problem-oriented approach, based on feelings of failure and unacceptable behaviour. Clients' own voices and perspectives are seldom heard, and although this is only the start of a long journey, we hope this dissertation can do its part in this change to a different approach for people who are labelled as opiate-dependent.

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Samenvatting

De laatste decennia wordt de visie op afhankelijkheid (van opiaten) meer en meer gekenmerkt door de overtuiging dat verslaving in de eerste plaats een chronische aandoening is, die gepaard gaat met perioden van herval en resulteert in langdurige, negatieve effecten op verschillende levensdomeinen. Bovendien wordt de meerderheid van de opiaatafhankelijke personen blootgesteld aan een aantal gezondheidsrisico's (vb. AIDS, hepatitis) als gevolg van hun drugmisbruik en het sterftecijfer binnen deze groep is aanzienlijk hoger dan binnen de algemene bevolking. Naast een aantal negatieve effecten op het niveau van de 'gebruiker', brengt opiaatafhankelijkheid eveneens een grote kost met zich mee voor de samenleving, o.a. omwille van de hoge werkloosheidcijfers binnen deze groep, oplopende gezondheidskosten en de betrokkenheid van opiaatafhankelijke personen in illegale activiteiten.

Bijgevolg deed zich tijdens het afgelopen decennium een paradigmaverschuiving voor binnen de verslavingszorg (van genezing naar zorg), die een medicalisering van de sector met zich meebracht. Meer en meer aandacht ging hierbij uit naar harm reduction of schadebeperkende interventies (vb. spuitenruil), die de schadelijke gevolgen van druggebruik voor de maatschappij en het individu tot een minimum proberen beperken. Één van de belangrijkste pijlers van deze benadering is het verstrekken van substitutiebehandeling aan mensen met een opiaatafhankelijkheid. Methadon is de standaard substitutiebehandeling voor opiaatafhankelijke personen in de meeste landen. De effectiviteit van methadonsubstitutiebehandeling is reeds meermaals aangetoond in verschillende internationale studies en methadon wordt dan ook beschouwd als een belangrijke, evidence-based succesfactor binnen de behandeling van opiaatafhankelijkheid. Het overgrote deel van deze studies is echter voornamelijk gefocust op sociaal wenselijke uitkomstmaten (vb. geen (bij)gebruik, geen illegale activiteiten), met beperkte aandacht voor aspecten die voor het individu zelf belangrijk zijn, zoals kwaliteit van leven. Dit is in schril contrast met studies bij personen met andere chronische aandoeningen zoals diabetes en kanker, waar het perspectief van de persoon zelf een prominente plaats heeft in de evaluatie en het proces van een behandeling.

Kwaliteit van leven vertrekt vanuit de subjectieve beleving van het individu. Het is dan ook een centraal concept binnen de gezondheidszorg voor mensen met chronische aandoeningen (geestelijke gezondheidszorg, mensen met een beperking, oncologie). Nochtans, specifiek binnen de verslavingssector is de aandacht voor dit concept en voor persoonsgerichte uitkomstmaten in het algemeen, uiterst gering. Het perspectief van mensen die drugs gebruiken, wordt

zelden aanhoord binnen verslavingsonderzoek, ondanks het feit dat dit zeer bruikbare informatie kan opleveren die de effectiviteit van onze hulpverlening ten goede zou komen. Daarnaast zou het ons ook inzicht verschaffen in de feitelijke impact van het volgen van een methadonbehandeling op de levenskwaliteit van een persoon.
Naast deze beperkte aandacht voor het cliëntperspectief, ligt de focus voornamelijk op drug- en gezondheidsgerelateerde aspecten, terwijl andere levensdomeinen (vb. sociale participatie, familie) meermaals genegeerd worden. Verder zien we dat ondanks de beperkte kansen op genezing van opiaatafhankelijkheid op korte termijn, aandacht voor langetermijnuitkomsten van een behandeling zo goed als onbestaande is.

Voorliggend doctoraatsonderzoek probeert aan bovengenoemde tekortkomingen tegemoet te komen door de beperkte kennis rond kwaliteit van leven binnen de groep van opiaatafhankelijke personen te vergroten, vertrekkende vanuit hun eigen perspectieven en ervaringen. In dit proefschrift staat de huidige kwaliteit van leven van opiaatafhankelijke personen, die minstens 5 jaar geleden een methadonbehandeling gestart zijn, voorop. Bijzondere aandacht gaat uit naar het perspectief van mensen met een opiaatafhankelijkheid zelf. Hun persoonlijke invulling van het concept 'kwaliteit van leven' vormt het uitgangspunt voor het verdere verloop van deze studie. De focus ligt op aspecten die de huidige kwaliteit van leven beïnvloeden en de impact van de gevolgde methadonbehandeling(en) hierop. Daarnaast trachten we na te gaan in hoeverre kwaliteit van leven een bruikbaar concept is als vertrekpunt en uitkomstmaat binnen de zorg en ondersteuning aan opiaatafhankelijke personen. De orthopedagogische invalshoek van dit proefschrift resulteert in een sterke focus op de praktijk en het handelen. Het integratief karakter ervan, leidt ertoe dat een combinatie van methoden (kwantitatief en kwalitatief) centraal staat in dit onderzoek. De uiteindelijke doelstelling van ons orthopedagogisch handelen is immers om de noden van een individu in een problematische situatie zo goed mogelijk te beantwoorden.

In een eerste studie (*Hoofdstuk 2)* gaan we aan de hand van negen focusgroep gesprekken met in totaal 67 druggebruikers, na hoe druggebruikers het concept ‘kwaliteit van leven’ zelf invullen, vertrekkende vanuit hun eigen beleving en ervaringen. Daarnaast wordt er onderzocht in hoeverre het theoretisch kader met betrekking tot kwaliteit van leven van Schalock (1996), dat vaak gehanteerd wordt in de ondersteuning van mensen met een beperking, toepasbaar is bij druggebruikers.
Druggebruikers beschouwen kwaliteit van leven in de eerste plaats als een ruim en multidimensioneel concept, dat niet hoofdzakelijk geassocieerd wordt met

gezondheid of gezondheidsgerelateerde aspecten. ‘Sociale inclusie’, ‘zelfbepaling’ en ‘persoonlijke relaties’ worden het vaakst vermeld als belangrijke domeinen van kwaliteit van leven. Vervolgens blijkt het theoretische kader van Schalock (1996), bestaande uit 8 domeinen, ook hanteerbaar bij druggebruikers. De interpretatie van de verschillende domeinen en een aantal beperkingen die deze negatief beïnvloeden, blijken echter specifiek te zijn voor de sociale situatie van druggebruikers (vb. het ontbreken van een blanco strafblad). Deze studie toont aan dat kwaliteit van leven eerst en vooral een multidimensioneel concept is, met een sterk contextuele component, dat een aantal belangrijke domeinen bevat die zelden opgenomen worden in verslavingsonderzoek (vb. zelfbepaling). Deze bevindingen laten ons toe om de persoonlijke invulling en definiëring van het concept kwaliteit van leven door druggebruikers beter te begrijpen en deze als startpunt te nemen voor ons verdere onderzoek.

De tweede studie (*Hoofdstuk 3*) is een systematische literatuurstudie van gepubliceerde studies in wetenschappelijke tijdschriften rond levenskwaliteit van opiaatafhankelijke personen. Aan de hand van deze studie proberen we een zo goed mogelijk zicht te krijgen op de bestaande kennis over kwaliteit van leven bij opiaatafhankelijke personen. Tevens besteden we aandacht aan de manier waarop kwaliteit van leven gedefinieerd wordt in deze studies en welke instrumenten er gebruikt worden om deze te meten. Daarnaast onderzoeken we hoe de kwaliteit van leven van opiaatafhankelijke personen zich verhoudt ten opzichte van andere doelgroepen, welke factoren hier een invloed op hebben en wat de impact van het volgen van een substitutiebehandeling is op iemands kwaliteit van leven.
Deze studie geeft aan dat er een grote discrepantie bestaat tussen de eigen definiëring van opiaatafhankelijke personen omtrent het concept ‘kwaliteit van leven’ en de huidige zienswijze binnen verslavingsonderzoek. De resultaten uit deze studie tonen aan dat kwaliteit van leven vaak gebruikt wordt als een overkoepelende term, die concepten als gezondheidsstatus en gezondheidsgerelateerde kwaliteit van leven omvat. Dit resulteert in een aantal studies die over hetzelfde concept spreken, maar eigenlijk verschillende zaken meten. Gezondheidsgerelateerde kwaliteit van leven meet de effecten van een ziekte op het dagelijkse functioneren van een persoon en wordt vaak gebruikt binnen de medische wereld om de afwezigheid van pathologie aan te tonen. Het concept kwaliteit van leven vertrekt echter vanuit de subjectieve beleving van een persoon, en diens tevredenheid met zijn leven in het algemeen en de verschillende levensdomeinen die hier deel van uitmaken. Onderzoek binnen de verslavingszorg focust vooral op gezondheidsgerelateerde kwaliteit van leven, zonder aandacht te geven aan de subjectieve beleving van een persoon. Naast het

inconsistente gebruik van het concept kwaliteit van leven, wordt een waaier van verschillende instrumenten gebruikt om kwaliteit van leven te meten, wat leidt tot een beperkte vergelijkbaarheid en een grote heterogeniteit van bevindingen uit de verschillende studies. Desondanks, is reeds meerdere malen aangetoond dat de kwaliteit van leven van opiaatafhankelijke personen laag is in vergelijking met de algemene bevolking, en meest vergelijkbaar met deze van personen met psychische problemen. Substitutiebehandeling blijkt een positief effect te hebben op de kwaliteit van leven van opiaatafhankelijke personen, vooral tijdens de eerste maanden van de behandeling. Studies die aandacht geven aan langetermijneffecten van een substitutiebehandeling op kwaliteit van leven zijn echter zo goed als onbestaande. Onderzoek naar determinanten of factoren die de kwaliteit van leven binnen de groep van opiaatafhankelijke personen beïnvloeden, zijn beperkt en de resultaten ervan eerder inconsistent. De tekortkomingen van het huidige onderzoek rond kwaliteit van leven en aandachtspunten voor verder onderzoek worden eveneens besproken.

In een derde onderzoeksluik wordt in een cross-sectionele studie met 159 participanten, de huidige kwaliteit van leven van opiaatafhankelijke personen en de hiermee samenhangende determinanten onderzocht. Hoofdstuk 4 gaat, aan de hand van een multidimensioneel instrument uit de geestelijke gezondheidszorg, dieper in op de huidige kwaliteit van leven van opiaatafhankelijke personen. Één van de bevindingen van deze studie is dat lage scores op een bepaald levensdomein niet noodzakelijk samengaan met lage scores op een ander levensdomein, wat de noodzaak aangeeft om kwaliteit van leven op een multidimensionele manier te meten. Daarnaast blijkt dat heel wat opiaatafhankelijke personen, minstens vijf jaar na het starten van een methadonbehandeling, nog steeds lage scores rapporteren op verschillende domeinen van kwaliteit van leven (vb. familie en financieel). Dit bevestigt de chroniciteit van opiaatafhankelijkheid en de impact ervan op verschillende levensgebieden. Een belangrijke positieve bevinding uit deze studie is dat opiaatafhankelijke personen, ondanks de chroniciteit van hun problematiek, een hoge tevredenheid rapporteren voor wat betreft zingeving. De participanten hebben een duidelijk toekomstbeeld, met bijhorende doelen waarnaar ze willen streven. Een derde van de participanten rapporteert echter lage scores voor wat betreft de tevredenheid met betrekking tot het vervullen van deze toekomstplannen.

Voor wat betreft de factoren die de kwaliteit van leven van opiaatafhankelijke personen beïnvloeden, blijkt dat de totale kwaliteit van leven vooral bepaald wordt door het psychisch welzijn van een persoon en een aantal psychosociale variabelen (vb. sociale steun) *(Hoofdstuk 4*). Dit is een belangrijke bevinding, gezien de grote mate van psychologische problemen binnen de doelgroep en de

sterke samenhang met iemands levenskwaliteit. Als we kijken naar domeinspecifieke determinanten van kwaliteit van leven zien we dat geen enkel levensdomein bepaald wordt door dezelfde combinatie van predictoren, wat opnieuw de multidimensionaliteit van het concept aangeeft (*Hoofdstuk 5*). De verschillende domeinen van kwaliteit van leven hangen vooral samen met een aantal psychosociale en persoonsgerelateerde variabelen en met tevredenheid met behandeling. De impact van gezondheidsgerelateerde variabelen is beperkt. In tegenstelling tot wat algemeen verondersteld wordt, toont onze studie aan dat er geen direct effect is van druggerelateerde variabelen op zowel de totale als de domeinspecifieke kwaliteit van leven van opiaatafhankelijke personen. Echter uit de padanalyses in hoofdstuk 5 blijkt dat er voornamelijk een indirect effect merkbaar is van huidig heroïnegebruik op een beperkt aantal domeinen van kwaliteit van leven. Dit indirecte effect wordt, afhankelijk van het levensdomein, vooral gemedieerd door psychosociale (vb. gestructureerde daginvulling) en behandelingsgerelateerde (vb. methadondosis) variabelen.
De resultaten van deze studie suggereren dat een verbetering van de kwaliteit van leven bewerkstelligd kan worden door het ondersteunen van opiaatafhankelijke personen in hun dagelijkse leven. Deze ondersteuning moet meer inhouden dan het verstrekken van een farmacologische behandeling en stelt ook de vraag naar aspecten als sociale inclusie, dagbesteding en psychologisch welzijn. Verder toont deze studie aan dat kwaliteit van leven een bruikbaar concept is in de klinische praktijk voor het verstrekken van een totaalbeeld over de levenssituatie van een persoon, op basis van zijn/haar eigen ervaringen en perspectieven en het verlenen van inzicht over de impact van een opiaatafhankelijkheid op iemands levenskwaliteit vanuit een holistische benadering (met aandacht voor de verschillende levensgebieden).

In een laatste studie (*Hoofdstuk 6*) trachten we aan de hand van diepte-interviews de impact van methadonbehandeling in kaart te brengen op belangrijke deelaspecten van kwaliteit van leven. Vertrekkende vanuit de persoonlijke verhalen van 25 opiaatafhankelijke personen gaan we op zoek naar belangrijke componenten van kwaliteit van leven die bij(ge)dragen (hebben) tot de periode in hun leven met de beste levenskwaliteit, vanaf het moment dat ze met hun methadonbehandeling gestart zijn tot de dag van vandaag. Op deze manier willen we aandacht geven aan de persoonlijke sterktes en steunbronnen van een persoon met respect voor de eigenheid van een individu. Hierdoor verleggen we de focus naar een sterktebenadering, die indruist tegen de heersende probleemgeoriënteerde focus binnen verslavingsonderzoek. Daarnaast bestuderen we de impact van het volgen van een methadonbehandeling op deze belangrijke componenten van iemands leven.

Vijf belangrijke thema's worden meermaals aangehaald als belangrijke componenten van een goede levenskwaliteit: 'het hebben van sociale relaties', 'psychologisch welzijn', 'het hebben van een bezigheid', 'onafhankelijk zijn' en 'een betekenisvol leven'. Net als in onze derde deelstudie, wordt het belang van een betekenisvol leven zeer sterk benoemd in de kwalitatieve interviews. Clean zijn of worden, wordt aanzien als een belangrijke voorwaarde om bepaalde componenten van een goede levenskwaliteit in vervulling te kunnen brengen. Daarnaast geven de bevindingen van deze studie weer dat opiaatafhankelijke personen dezelfde dingen belangrijk achten als de algemene bevolking, maar dat zij vaak geconfronteerd worden met een aantal beperkingen, eigen aan hun levenstijl, die een goede levenskwaliteit bemoeilijken. Participanten vermelden een aantal positieve effecten van methadon op hun levenskwaliteit, zoals normaal kunnen functioneren en niet langer afhankelijk zijn van illegale drugs. Daarnaast worden ondermeer stigma, discriminatie en afhankelijkheid van methadon vaak vermeld als negatieve consequenties van het volgen van een methadonbehandeling. Als een gevolg hiervan hangt een goede levenskwaliteit voor de meeste participanten samen met methadonvrij zijn en onafhankelijk zijn van eender welk product. Methadon wordt vaak beschouwd als een manier om een zekere periode in hun leven te overbruggen en in tussentijd de nodige ruimte en tijd te hebben om een aantal belangrijke aspecten van kwaliteit van leven (vb. sociale relaties) verder uit te bouwen.
De bevindingen van deze studie illustreren de ambivalente invloed van methadon op belangrijke componenten van iemands levenskwaliteit. Wij suggereren dan ook om voldoende aandacht te geven aan de sociale en praktische consequenties van het volgen van een methadonbehandeling.

In de algemene discussie (*Hoofdstuk 7*) komen we terug op de belangrijkste onderzoeksbevindingen en bespreken we de klinische implicaties die deze met zich meebrengen ter bevordering van de kwaliteit van leven van opiaatafhankelijke personen. Ten slotte gaan we in op de algemene beperkingen van dit proefschrift en doen we een aantal aanbevelingen voor verder onderzoek.