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## **CHAPTER 9**

### **General Discussion**

The overall aim of this thesis was threefold. The first aim was to describe the utilization of Youth Mental Health Care (YMHC) in the Netherlands: whether there are differences in this utilization between ethnic groups, between children and adolescents, between males and females, and whether socioeconomic factors play a role in this utilization. The second aim was to describe ethnic differences with regard to the DSM-classifications of the patients. And the third aim was to analyze ethnic differences in premature termination of therapy of YMHC patients.

A general underutilization of YMHC services has frequently been described (Boon et al., 2014; Meltzer et al., 2000; Zachrisson et al., 2006). Because youth psychiatric disorders can cause serious damage later in life, it is of utmost importance to gain knowledge on the causes of underutilization of YMHC (Alonso et al., 2013; Domburgh, 2009; Dulmus & Wodarski, 1996; Gosden et al., 2003; Kazdin & Wassell, 1998; Sytema et al., 2006). In several countries, underutilization of YMHC was shown to be substantially higher for ethnic minority youth than for their ethnic majority peers (V. C. Copeland, 2006; Garland et al., 2000; Goodman et al., 2008; Ivert et al., 2013; Kodjo & Auinger, 2004). In addition, psychiatric disorders are often under- or misdiagnosed, especially in ethnic minority youth (Begeer et al., 2009; Crone et al., 2010; Kreps, 2006; Martin, 1993; Reijneveld et al., 2005; Van Ryn & Fu, 2003). Another important factor that contributes to psychiatric disorders not being (correctly) treated, is the fact that many treatments are not completed (Baruch et al., 2009; Lai et al., 1998; Luk et al., 2001; Midgley & Navridi, 2006). When children drop out of psychiatric treatment, their disorders might persist or even worsen later in life (W. E. Copeland et al., 2013; Dulmus & Wodarski, 1996; Gosden et al., 2003; Reis & Brown, 1999). In order to prevent these negative consequences of treatment dropout, it is important to gain knowledge of its determinants.

Three data sources were used: data of a patient population, data of the general population in the same area (for the empirical studies), and data of published studies on dropout (for the review and meta-analytic study). For the patient population, data were used of all patients that were registered at two YMHC institutions in The Hague (i.e., *De Jutters*, a general YMHC institution, and *i-psy de jutters*, an intercultural specific YMHC institution) in 2008 and 2009. The data of the general population of The Hague and its surroundings in 2008 and 2009 were drawn from municipality files. Data of all published studies (1994-2013) on dropout in child and adolescent psychiatry were used to conduct a meta-analytic review and a literature review. In this general discussion the main findings of the whole study are summarized and

interpreted, limitations are addressed, and implications for clinical practice and future research are suggested.

### **Summary of findings**

After the introduction in the first chapter, we described the utilization of YMHC services for the different ethnic, age and gender groups in The Hague in the second chapter. Because at the time of this study the two described institutions were the only two existing YMHC institutions in The Hague, we had almost complete information of all youths that received YMHC treatment in that city. It might be that some youth receive YMHC outside of The Hague and were not included in our analyses. There is no reason however to expect that these are especially patients from specific ethnic (minority) groups, and therefore the proportion of utilization rates between ethnic groups will not differ significantly from the rates presented in this study. We analyzed the ethnic composition of the total patient group of the two YMHC institutions in 2009, and compared this to the general population of The Hague. Relative risk ratios (likelihood) of YMHC utilization for ethnic minority groups were calculated with the native Dutch youth as the reference group. Age specific and gender specific results were presented. The results showed that the use of YMHC services was unequally distributed over the different ethnic, gender and age groups. During childhood (age <12) most groups of ethnic minority girls and boys were less likely to use YMHC than native Dutch boys and girls. Nevertheless, native Dutch girls also made less use of YMHC institutions than would be expected according to the estimated prevalence rates of psychiatric disorders. Only for native Dutch boys the utilization percentage was approximately equal to the estimated prevalence rate of psychiatric disorders. During adolescence, all ethnic groups were equally underrepresented in YMHC. The results thus indicated that adolescents of all ethnic groups, including the native Dutch, are being poorly reached by YMHC.

In the third chapter, the association between ethnic background, socioeconomic status (SES) and YMHC utilization was investigated by analyzing the percentage of YMHC patients per district of The Hague. In addition, the number of youth inhabitants per district, the ethnic background of the inhabitants, and the district's average spendable year income were retrieved from municipality files. The average spendable annual income per district was used as an indicator for SES, and the percentage of native Dutch inhabitants was used as an indicator of the ethnic composition of that district. The results indicated that the percentage of children and

adolescents in treatment was strongly associated with ethnic composition of the districts, and that the district's income level had almost no effect. Findings thus suggest that on district level, ethnic composition is more relevant in the utilization of YMHC than socioeconomic aspects. Because no information about the SES of the patients was available, the possibility remains however that on an individual level socioeconomic factors do play a role. For instance, within districts with a low average year income, ethnic minority youth with a higher SES might enter care more easily than minority youth with a lower SES.

In the fourth chapter differences between ethnic groups in the received DSM classifications of the patients of the two YMHC institutions were assessed. Odds ratios (chances) on DSM-classifications for ethnic minority patients were calculated with the native Dutch patients as the reference group. The patients were divided into two groups: 1) a group of patients with only V-codes, indicating that no classification of a psychiatric disorder was registered. 2) a group of patients diagnosed with one or more psychiatric disorders on Axis I. Within this second group, a subcategory of patients with more than one psychiatric disorder (i.e., comorbid disorders) were identified. The results showed that, compared to native Dutch patients, ethnic minority patients received co-morbid diagnoses less often. In contrast, ethnic minority patients more often received V-codes only, indicating that problems such as 'relational or communication problems between child and parent' or 'other social/environmental problems' were identified as the main reason for treatment. It is possible that these V-codes were only given temporally because clinicians needed more time to decide on a certain diagnoses. Therefore the patients were exclusively allocated to the group of 'only V-codes' when during the whole period of treatment the V-code remained the only classification.

From the fifth chapter on, the focus shifted to the way treatments are terminated. A meta-analytic review and a literature review on premature termination or dropout were done and described in the fifth and sixth chapter. Randomized control trial (RCT) studies (efficacy designs) were compared with practice-based studies (effectiveness designs). In addition, we compared studies that used a dropout definition based on the opinion of therapists with those that took the number of predetermined completed sessions as a criterion. The meta-analytic review (chapter 5) showed that dropout percentages were influenced by study design, i.e. percentages were lower in RCT studies than in practice-based studies. Within practice-based settings, the dropout percentages were lower when the therapist's opinion was used than when a predetermined number of sessions was used as the dropout criterion. In RCT studies on the

other hand, the dropout percentages were similar for studies using the first or the second definition. Additionally, we studied three groups of predictors, i.e. pre-treatment child variables, pre-treatment family/parent variables, and treatment/therapist variables. It appeared treatment/therapist variables (e.g., therapeutic relationship) were overall stronger dropout predictors than the pre-treatment child variables and pre-treatment family/parent variables (e.g., ethnic background, family composition).

In the sixth chapter, a literature review was conducted with the goal to structuralize the knowledge on psychotherapy dropout with ethnic minority youth. This review showed there was an increased dropout chance for some ethnic minority patients compared to ethnic majority patients. Especially an African American background was shown to increase the dropout chances, although results were inconsistent. Therefore firm conclusions could not be given. Also, the results indicated that an Asian American or a Hispanic/Mexican American background may not be a risk factor for dropping out. The results were again inconsistent however, and there were too little studies that analyzed Hispanic/Mexican Americans and Asian Americans as separate groups. Because most of the studies were done in the United States, much remains unclear about ethnic minority background being a risk factor for dropping out in other countries. A second conclusion is that predictors of dropout differ between ethnic groups. For instance, some child and family pre-treatment variables predicted dropout in Caucasian families but not in African American families. For Hispanic families, an unbalanced therapeutic alliance (measured during the first session) was found to relate to dropout, while this was not so for Caucasian families. Next, the results indicated that for none of the ethnic groups, a lower socioeconomic status is a risk factor for dropping out. It also appeared that an ethnic match between therapist and the parent or the patient lessened the chance to drop out in some, but not in all cases. For instance, the age of the patient was an important factor in the effect of the presence/absence of an ethnic match between the patient and the therapist, i.e., an ethnic match decreased the dropout risk for adolescents but not for children.

In the last two chapters, several risk factors for dropout were analyzed within the two YMHC settings in The Hague. The study described in chapter 7 was conducted as *De Jutters*. Three dropout risk factors (ethnic minority status, a lower socioeconomic status (SES), and higher problem severity) were examined for children and adolescents separately. Termination status was divided in three categories: 1) referred patients (i.e., referred to another department of the YMHC institution or to another youth care facility outside YMHC); 2) dropouts; and 3)

completers. The results showed that for children, Moroccan ethnicity and higher externalizing scores were risk factors for being referred. For adolescents, Surinamese ethnicity, being older, and lower SES levels were risk factors for dropout. Chapter 8 focused on another dropout risk factor; the quality of the therapeutic relationship. This study was conducted at *i-psy de jutters*, where only patients with an ethnic minority background are treated. The results indicated that a perceived increase in quality of the therapeutic relationship during the course of therapy was associated with patients completing therapy, while a perceived decrease in quality of the therapeutic relationship during the course of therapy was associated with patients dropping out.

### **Interpretation of findings**

To determine who is in need for psychiatric care, several authors propose to use impairment criteria in addition to meeting symptom criteria, i.e., a mental health problem that causes impairment in daily functioning to such a degree that treatment in mental health care is needed (Brauner & Stephens, 2006; Evans et al., 2013; Reed, Correia, Esparza, Saxena, & Maj, 2011; Roberts et al., 1998). Two surveys among psychiatrists and psychologists worldwide showed that most clinicians agree that concepts of severity and impairment are essential to be included in disorder classification systems, although there was little agreement as to how or why (Evans et al., 2013; Reed et al., 2011). With respect to children and adolescents, too little research on prevalence rates has been done to warrant firm conclusions. Still, estimations of prevalence rates adjusted for impairment can be used for the purpose of the interpretation of our findings. Especially because prevalence rates appear to be quite similar across countries and across ethnic groups (Ivanova et al., 2007; Rescorla et al., 2007; Rutter & Stevenson, 2008). Typically, the prevalence rates adjusted for impairment are less than half the prevalence rates based on only meeting symptom criteria (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003; Fombonne, 2002; Ford, Goodman, & Meltzer, 2003; Friedman et al., 1996; Heiervang et al., 2007; Merikangas et al., 2010; Roberts et al., 1998; Roberts, Roberts, & Xing, 2006; Verhulst, Van der Ende, Ferdinand, & Kasius, 1997). To determine who is in need of treatment in a YMHC facility, and thus to determine whether underutilization is present, the prevalence rates adjusted for impairment and need for treatment should be used (see table 1). Of course, these are only estimations and we cannot give a definite picture on to what extent different groups of youth (e.g., with respect to ethnic background, age, gender, type of disorder) are receiving the care they need. In addition, some might receive non-psychiatric care outside of YMHC facilities which

can be sufficient for them. Still, the estimated adjusted prevalence rates are functional for our goal; to determine the differences between ethnic groups, between children and adolescents, and between boys and girls in the (possible) underutilization of YMHC.

*Table 1: Prevalence rates of psychiatric disorders*

	Children		Adolescents	
	Girls	Boys	Girls	Boys
Prevalence rates (%)	5-11	8.7-22	7.5-17	13.5-17
Adjusted prevalence rates (%)	2.5-5.5	4.5-11	3.5-9	7-9

*Table 2: YMHC utilization percentages*

Ethnic background	Children		Adolescents	
	Girls	Boys	Girls	Boys
Native Dutch	3,2	8,4	3,2	3,1
Surinamese	2,4	5,4	3,8	2,6
Turkish	1,7	4,5	2,6	2,5
Moroccan	0,8	4,0	2,3	2,1
Antillean and Aruban	2,3	7,4	3,4	2,9
Other African	2,1	4,2	3,3	2,9
Other western	1,9	4,0	2,9	1,9
Other non-western	2,6	3,6	2,9	3,2
Total	2,6	6,5	3,1	2,8

The average YMHC utilization rate for female children in our study is 2.6% (see table 2). As the adjusted prevalence rates range between 2.5% and 5.5%, this indicates there might be an overall minor underutilization of YMHC for girls. For native Dutch girls (utilization percentage of 3.2), and in a lesser extent for other non-western girls (utilization percentage of 2.6) the underutilization may not be present. For the other ethnic minority girls (i.e., Moroccan, Turkish, Surinamese, Antillean/Aruban, other African, other western) the underutilization seems to be present though (utilization percentages ranging from 0.8 to 2.4).

The average YMHC utilization rate for male children in our study is 6.5% (see table 2). The adjusted prevalence rates ranged between 4.5% and 11%, indicating there might not be an overall underutilization of YMHC for male children. This especially accounts for Dutch,



Antillean/Aruban, and Surinamese boys for whom the utilization percentages are 8.4, 7.4, and 5.4. This does not account for the other five ethnic groups (i.e., Turkish, Moroccan, African, other non-native western, other non-western) where utilization percentages are much lower (ranging from 3.6 to 4.5). For these last five ethnic minority groups there might thus be underutilization. The average YMHC utilization rate for female adolescents is 3.1% (see table 2), which indicates an overall underutilization for this group (adjusted prevalence rates range from 3.5% to 9%). Again, this underutilization is not extremely high though. Here no clear differences between ethnic groups are found. The average utilization rate for male adolescents is 2.8% (see table 2), which indicates the highest rate of underutilization of YMHC (adjusted prevalence rates range from 7% to 9%). Again, this accounts for all ethnic groups, including the native Dutch adolescent boys.

#### *The pathway to YMHC for children*

As we have seen, the chances for ethnic minority children to receive YMHC are somewhat lower than for their ethnic majority peers. In this paragraph we will focus on the possible explanations for these results by using the Filter Model introduced in the first chapter (Goldberg & Huxley, 1980). The paragraph hereafter will focus on the situation with adolescents.

An important role in the process of help-seeking (*first filter*) for children is played by the parents, relatives and teachers. Several important predictors for help-seeking are the strain of caring for the child, as perceived by the caregiver or teacher (Angold et al., 1998; Brannan, Heflinger, & Bickman, 1997), and the perception of need for services (Zahner & Daskalakis, 1997). There appear to be significant and robust ethnic differences in experienced caregiver burden or strain. In the studies of McCabe et al. (2003) and Shin and Brown (2009), African Americans reported significantly lower caregiver strain than did Caucasians. The effects of ethnic background on YMHC utilization were indirect, mediated through caregiver strain, and a lower experienced caregiver strain resulted in lower YMHC utilization. Such differences might be found within the various ethnic populations living in the Netherlands as well.

Another important predictor of help-seeking is the level of proto-professionalization (the degree to which individuals have the capacity to obtain, process, and understand basic health information, recognize mental health problems, and have knowledge about the services needed to make appropriate health decisions) of the caregiver (or teacher) which influences the capacity to recognize problems and the knowledge where to seek help (De Swaan, 1979). Ethnic

minorities appear to be less familiar with mental health problems and with the possibilities of professional care than majority groups (De Jong & Colijn, 2010). Also, there are ethnic differences in the recognition or identification of a mental health problem. For instance, emotional problem identification was lower among several groups of ethnic minority parents than among native Dutch parents (Bevaart et al., 2012; Verhulp et al., 2013). This lower problem identification could (partly) explain why ethnic minority parents less often seek help for the mental problems of their child than majority parents. Alternatively, they may seek help with their GP without mentioning the mental health problems and focus instead on somatic problems (Gureje, Simon, Ustun, & Goldberg, 1997; Keyes & Ryff, 2003; Krueger, Chentsova-Dutton, Markon, Goldberg, & Ormel, 2003). Although the assumption that ethnic minority groups tend to somatize more often than ethnic majority groups is certainly not supported by all studies (Aragona et al., 2005; Parker et al., 2005). In addition, ethnic minority parents also tend to seek help with traditional or alternative healers instead of their GP or another regular care worker (Bhui & Bhugra, 2002).

Of course, not only factors in the help-seeking process play a role in the underutilization of YMHC services. Usually help is first sought at the GP or a primary care worker. Consequently, factors that are associated with their recognition of psychiatric problems (*second filter*), and subsequent referral (*third filter*) should also be considered (Zwaanswijk, Verhaak, Van der Ende, Bensing, & Verhulst, 2005b). For instance, these professionals are likely to judge differently on behavioural and psychological cues dependant on the ethnic background of the patient, the ethnic background of the professional, cultural values and education of the professional, as well as the culture of the institution itself (Torres et al., 2007; Zayas et al., 2005). As a result, ethnic minority children with psychiatric disorders may be less likely to be referred to YMHC and are treated elsewhere (e.g., in primary youth care) or not treated at all. Once a child is referred to YMHC, it is helpful when the parents are familiar with the mental health care system and have confidence in their possibilities to seek help at the YMHC institution. This familiarity and confidence is less apparent for ethnic minority parents than for native Dutch parents (Boon & Colijn, 2001; Zwaanswijk et al., 2003, 2005a). In one study it was found that in primary care there were no ethnic differences in referral to YMHC by the professional, while after referral there were ethnic differences in the utilization of YMHC (Bevaart et al., 2012). This indicates that many children, especially ethnic minority children, do not access the recommended mental health services after referral (the so-called no show).

### *The pathway to YMHC for adolescents*

For adolescents, the studies in this thesis showed there were no ethnic differences in YMHC utilization. This was also found by Zwaanswijk et al. (2003), where adolescents of ethnic minority descent were even more likely to have received mental health care than native Dutch youth, although the number of ethnic minority adolescents was rather small in their study. It might be that adolescents in general are more reluctant to seek help than parents (Rickwood, Deane, Wilson, & Ciarrochi, 2005; Zachrisson et al., 2006). Even when they recognize their own problematic behavior and feelings, they are still less likely than adults to translate their concerns into help-seeking actions (Sourander et al., 2001; Zwaanswijk et al., 2003). The absence of differences in utilization rates between ethnic groups could, among other things, be the result of equal levels of proto-professionalization and similar help-seeking processes among ethnic groups at this age (*first filter*). For example, it was found that the level of problem recognition (which is an indicator of proto-professionalization) did not differ as much between ethnic minority adolescents and native Dutch adolescents, as it did between ethnic minority parents and native Dutch parents (Verhulp et al., 2013). In addition, adolescents from all ethnic groups have similar access to (mental) health-related information via media such as television, magazines, and internet (Schalken, 2010), and they often seek help via internet health services or e-health sites where they find information about their potential disorders (Andreassen et al., 2007). Also, many high schools offer school-based services which might be a sufficient mental health provider for at least part of the adolescents in need for mental health care (Farmer, Burns, Phillips, Angold, & Costello, 2003; Taal & Dudink, 2006). When adolescents do decide to seek help with a GP or youth care worker, these professionals experience difficulties in recognizing mental health problems and subsequent referral to YMHC (*second and third filter*) in adolescents in general. For instance, Zachrisson et al. (2006) found that nearly half of the help-seeking adolescents with mental health problems were not being referred to YMHC.

An important related issue is that (some groups of) ethnic minority boys are found to have a much higher chance to be treated in forensic YMHC settings than their majority peers (Boon et al., 2014). And several surveys showed that, compared to ethnic majority boys, ethnic minority boys are overrepresented in judicial youth institutions (Bovenkerk & Yeşilgöz, 2003; Vollebergh, 2003). Research also showed that among juvenile male delinquents in the Netherlands and Germany, a high percentage meets the criteria for at least one psychiatric disorder, and high comorbidity rates are present (Köhler, Heinzen, Hinrichs, & Huchzermeier, 2009; R.R.J.M.;

Vermeiren, 2003; Vreugdenhil, Doreleijers, Vermeiren, Wouters, & Van den Brink, 2004). A hypotheses is that because early mental health care is lacking, especially for ethnic minority youth, the problems of these youth get worse during the years. During adolescence these youth express delinquent behaviour related to their psychiatric and behavioural problems, and judicial procedures are then indicated.

Contrary to the results in this thesis, two studies did find ethnic differences in the regular YMHC utilization rates for adolescents, with ethnic minority adolescents making less use of YMHC than ethnic majority adolescents (Cummings & Druss, 2011; Verhulp et al., 2013). In these two studies however, adolescents from the general population were asked about their mental health care utilization in the past year. While in this thesis, the data of the actual YMHC patients in a certain year were analyzed. Self-reports of adolescents or their parents on YMHC utilization might not always be accurate, and we think that our utilization rates are more likely to reflect the actual rates.

#### *Children and adolescents within YMHC: the diagnostic process*

When the first three filters are passed, patients are assessed by YMHC professionals. As we saw in the fourth chapter, the ethnic background of the patient is an important factor in the way patients are assessed. Ethnic minority patients were classified less often with a psychiatric disorder or comorbidity and more often with a V-code only (i.e., no classification of a psychiatric disorder was registered) compared to their majority peers. Because research has shown psychiatric disorders to be at least as high among ethnic minority youth as among ethnic majority youth, this lower classification of psychiatric disorders might be caused by several biasing mechanisms. For instance, ethnic differences in received diagnoses might be the result of a deficiency in the cross-cultural reliability of diagnostic categories or in the diagnostic abilities of the professional. Several studies found biases in the assignment of diagnoses to ethnic minority individuals (Begeer et al., 2009; Mandell et al., 2009; Neighbors, Trierweiler, Ford, Ford, & Muroff, 2003; Trierweiler et al., 2000; Yeh et al., 2002). Professionals might judge differently on behavioral and psychological cues based on the ethnic background of the patient, the ethnic background of the professional, cultural values and education of the professional, and the culture of the YMHC institution itself (Angold & Fisher, 1999; De Jong, 2010a; Garb, 2005; Torres et al., 2007; Zayas et al., 2005). In addition, unfamiliarity of the ethnic majority professional with the cultural norms of ethnic minority groups makes the clinician vulnerable to

their own personal biases (De Jong & Van Ommeren, 2002; Neighbors et al., 2003). As a consequence, ethnic minority youth might not be diagnosed correctly and thus not be treated for the right disorders. Diagnostic accuracy was found to be an important precursor to successful treatment, resulting in a better therapy engagement, fewer therapy no-shows, and a decreased likelihood of therapy dropout (Jensen-Doss & Weisz, 2008). Some critics advocate that a more culturally sensitive approach to psychiatry is needed, as current diagnostic guidelines have a fundamentally Euro-American outlook (Kress et al., 2005; Widiger & Sankis, 2000; Zandi, Havesaar, Laan, Kahn, & Van den Brink, 2011; Zandi et al., 2008). In two studies among psychiatrists and psychologists worldwide, substantial percentages reported problems with cross-cultural applicability and cultural bias of the current diagnostic classification of mental disorders (Evans et al., 2013; Reed et al., 2011).

Another issue is the necessity of accurate information about the child's problems given by the patient as well as other informants (e.g., parents, other family members, teachers), since psychiatric diagnosis relies heavily on self-report (Neighbors et al., 2003). Often ethnic minorities are less willing or less capable to share information on the development of their child, and it is therefore much harder to decide on a correct diagnoses (Pels & Nijsten, 2003). In addition, ethnic minorities (especially the parents) can have a weak knowledge of the host countries language, express problems and symptoms in different ways, and some words can have different meanings within the various languages (Nikapota & Rutter, 2008). Research has also shown it might depend on the specific informant how and to what extend the problems are reported. For instance, Moroccan boys reported much lower externalizing problems levels than did their teachers (G. W. J. M. Stevens et al., 2003), and Moroccan and Surinamese parents reported less problems with their children than did their teachers (Zwirs et al., 2006a). The differences in reported problems between teachers and native Dutch youth or parents were much lower.

#### *Children and adolescents within YMHC: dropping out of therapy*

Once children and adolescents have started treatment in YMHC, completion is important because this increases the likelihood that psychiatric problems get resolved. In the fifth chapter, a meta-analytic review of dropout studies was conducted. Several robust overall predictors for dropout were found. Ethnic minority status was one of these predictors, although only a minority of the dropout studies included ethnic background as one of the possible predictors. A

literature review specifically focusing on the dropout studies that did take ethnic background into account was conducted in chapter six. Mainly conflicting results were found. Therefore only some minor conclusions on the role of ethnic background in therapy dropout could be given. First, in the United States it depends on the specific ethnic background whether ethnic minority patients have a higher chance to drop out than ethnic majority patients. Whether ethnic minority background is a risk factor for dropping out in other countries than the United States remains unclear. Second, although several differences in dropout predictors between the ethnic groups were found, it should be noticed that results were often only found in one or two studies and were seldomly confirmed by others. The meta-analytic review further indicated that treatment/therapist variables were overall stronger dropout predictors than pre-treatment child and family/parent variables, which is in accordance with the theory of barriers to treatment participation (Kazdin et al., 1997a; Kazdin et al., 1997b). In this theory it is proposed that families experience multiple barriers during therapy interfering with participating in treatment, and that these experiences increase the risk for dropping out. Important practical implications for reducing therapy dropout can be deducted from the findings in this thesis and this theory. For instance, when the patient or parent experiences a bad relationship with the therapist, the therapist can try to positively influence this relationship or there could be a change in therapists, hopefully reducing the dropout chance. The finding of our meta-analytic review that treatment/therapist variables are the most important dropout predictors thus implicates that there are ways to reduce the chance of dropping out in the future.

Because only a minority of the studies on dropout in child and adolescent psychiatry focused on ethnic minority youth and only none of these studies was conducted in The Netherlands, several dropout predictors were studied at the our YMHC facilities in The Hague in chapter seven and eight. The hypotheses that different dropout risk factors would be found for children and adolescents, and different risk factors would be found for dropouts versus referrals, were confirmed in chapter seven. We considered that patients who are referred before therapy has ended cannot be seen as completers nor dropouts, because the treatment is being continued elsewhere (Armbruster & Fallon, 1994; Johnson et al., 2008), as it is not known how the patient will ultimately terminate therapy. The aggregation of referral patients and other termination groups in the majority of earlier dropout studies may have clouded interpretation of results on dropout predictors. Our results also indicated that ethnic minority status is not always a dropout predictor, as only some specific ethnic groups had higher dropout chances than the

majority group (i.e., Surinamese adolescents had higher dropout chances). This is in accordance with the results of former studies (see literature review in the sixth chapter). The higher dropout risk for Surinamese adolescents may, among other things, be explained by (Creole) Surinamese families often being single-parent families with only the mother living at home (Distelbrink, 2000). During adolescence these mothers may have less authority over their children, resulting in rebellious adolescents who prematurely terminate therapy. Also, because of the single-parent status, mothers all too often have to work long hours. As a result, no parent is present at home to motivate their child to participate in therapy.

Another finding was that Moroccan children had a higher chance to be referred. This might be explained by the difficulties some clinicians experience in working with Moroccan families (Bellaart, 2004). We therefore analyzed the sites where the Moroccan patients were referred to. It appeared most patients were referred to a specific mental health care site for youth with (mild) intellectual disabilities. Unfortunately no information was available on the appropriateness of the referral and its consequences for the patient. Maybe many of the Moroccan patients in our research group had psychiatric problems that were associated with intellectual disabilities, or these patients were seen intellectually disabled because they (or their parents) have a lower mastery of the Dutch language (Verboom, 2010). The finding that adolescent patients from unemployed parents had the highest chance to drop out, might indicate practical obstacles (e.g., insufficient money to pay for transportation). Also, in these unemployed families many other problems (e.g., parents having mental health problems themselves, upbringing problems, stress because of financial problems) may have hampered treatment participation. Because all Dutch children (from all ethnic backgrounds) are covered by public or private health insurance, utilization of health care services is largely independent from financial constraints (Zwaanswijk, 2005). Therefore financial constraints were not expected to play a significant role in therapy continuation. Our results suggest there are factors related to unemployment (and not related to whether the therapy can be paid for) that play a significant role in treatment dropout with adolescents.

The finding that both ethnicity and SES had a predictive value for dropout is an interesting addition to the role of ethnicity and SES in (youth) mental health care. Because both variables are correlated, many authors state SES variables actually explain the differences (on for instance prevalence of psychiatric disorders or accessibility of mental health care institutions) between ethnic groups, or we are actually talking about ethnic or cultural variables when SES differences

are found (Cooper, 2002; Kamperman et al., 2007; Stronks & Kunst, 2009; Stronks et al., 2001). Our study does not confirm nor invalidate these statements. It was rather found both variables are important and independent contributors for dropout.

An additional risk factor for dropout was a perceived decreasing quality of the therapeutic relationship, while a perceived improving quality of the therapeutic relationship during the course of therapy was associated with completing therapy. The few former studies (chapter five) that focused on the association between the quality of the therapeutic relationship and the completion or dropout of therapy also found this association. In these studies no specific focus was given to the ethnic background of the patients however, i.e. most of the time only ethnic majority patients were considered or ethnic background was not mentioned. In addition, it were mostly studies on substance abusing adolescents, and the quality of the therapeutic relationship was often measured in retrospect at the end of therapy, or by trained observers who rated the therapeutic alliance at one or two therapy sessions during the course of therapy. For this last approach, a research setting is needed, and it is therefore not useful in clinical practice. Our study in the eight chapter of this thesis on the contrary, was done in a clinical practice setting, which adds insights on the role of the therapeutic relationship in these settings. Our study revealed the quality of the therapeutic relationship plays an important role in therapy with ethnic minority youth, just as it does with ethnic majority youth. It also showed that a rather short instrument, which can be easily applied in clinical practice and which is completed by the child or adolescent patient, can be a valuable tool to measure the quality of the therapeutic relationship in therapy with ethnic minority youth.

### **Limitations and future research recommendations**

A first limitation of our study is it was mainly based on the data of two institutions in one large city in The Netherlands. We therefore do not know to what extent specific factors of these institutions, the population of The Hague, or even The Netherlands, may have influenced the results. For instance, utilization of (mental) health care services in the Netherlands is largely independent from financial constraints, because all Dutch children are covered by public or private health insurance (Zwaanswijk, 2005). The results may thus not be directly applicable to nations in which major financial constraints hamper the availability of care. We therefore advocate that research about ethnic differences in the utilization of YMHC is replicated in other cities in The Netherlands and in other countries.



Second, because our study was conducted in a daily clinical practice setting, we had no influence on who entered care and thus participated in our study. Neither did we have influence on the way diagnoses were made. As we saw, only a minority of youth that needs care enters YMHC, and information about the group that does not enter care is lacking. We can therefore not rule out the possibility that, for instance, differences in referral patterns between ethnic groups have influenced our results on diagnoses and dropout predictors. The goal was to evaluate the clinical practice of YMHC however, and we therefore conducted a practice-based study. We however have no clear picture of how and why some children do enter YMHC and others do not, and of the accuracy of this selection. Some children might be erroneously referred while other children that definitely need YMHC will never be referred. In addition, we have no clear picture on how many children receive (mental health) care elsewhere and which forms of care these exactly are. Only with all this additional information can we reach definite conclusions and recommendations on how to increase the accessibility of YMHC for those who need it, and minimise the number of children and adolescents coming into YMHC who do not need it.

A third limitation is our definition of socioeconomic status (SES), which may limit the comparison with other studies on the role of SES. For instance, in our third chapter, we used the average income of the district as an indicator for SES, and we did not have information on the individual SES levels of the patients. We could thus not provide rates of children with a lower or higher SES in care, and we can therefore not conclude socioeconomic factors do not play a role at all in the utilization of YMHC facilities. In our study described in the seventh chapter we were able to use individual SES variables (education level and occupation level of the parents). Here a specific subgroup of patients was concerned, while in our study described in the third chapter all the patients of our institution were included. We recommend to use similar indicators of individual SES levels in future studies.

Fourth, our study was conducted in 2008 and 2009 when it was still allowed to classify a patient with a V-code as the main diagnosis. In the years after that, the health care insurers (who are the main financers of mental health care in The Netherlands) decided it was not permitted to classify a patient with a V-code as the main diagnosis. Because of this rule, patients with 'only V-codes' will now not exist anymore. Similar results as found in our study can thus not be replicated, and the question is whether and what type of ethnic differences will be found in the

DSM classifications in YMHC practice nowadays. We therefore recommend a similar study on possible ethnic differences in DSM classifications in YMHC to be replicated.

Fifth, we only analyzed the child-therapist relationship and we did not analyze the parent-therapist relationship. Some former studies found that only parent-therapist relationship was predictive for dropout and not child-therapist relationship (Hawley & Weisz, 2005). As noted by Shirk and Karver (2003), the examination of the therapeutic relationship in child and family therapy may be more complex than in adult therapy, in part because it involves both child and caregiver relationships with the therapist. Even in the most child-focused interventions, caregivers are involved at some level throughout treatment; at the least, caregivers are responsible for getting the child to therapy and for structuring the family environment in ways conducive to the therapy recommendations (Hawley & Weisz, 2005). It might be best to have both the parent and the patient as the respondents (Zack et al., 2007) in order to get the patient's and the parent's perspective on the quality of the therapeutic relationship. Similarly, it would have been informative to include therapist reports of the quality of the therapeutic relationship as well. We recommend this should be done in future studies.

Also, we only analysed the therapeutic relationship in a group with ethnic minority patients, and we could not compare this with results for ethnic majority patients. We thus recommend research on the association between dropout and the therapeutic relationship in samples consisting of both ethnic majority and ethnic minority children and adolescents, so the results between the various ethnic groups can be compared.

Another limitation concerns the dropout definition. In contrast to our definition, many previous studies define dropout in terms of treatment duration or number of sessions completed, in which clients attending less than the specified number of sessions are categorized as dropouts. Both treatment completion and dropout can however occur after any number of sessions. We therefore chose to use a definition in which dropout could occur at any moment during therapy, as was also done in a minority previous studies (i.e., 'the termination of treatment at any point of time after inscription that occurs on the child's or parent's unilateral decision, while the therapist thinks further treatment is needed'). Such a definition has drawbacks as well though. For instance, when the therapist thinks that additional therapy is needed but the parent or patient feels that they have already benefited enough from therapy, it is uncertain whether these patients should be counted as dropouts or completers. Dropout thus remains a complex phenomenon, and all the different definitions make it almost impossible to

compare the results from the various studies. We recommend all future studies use a similar dropout definition in which both the opinion of the therapist as well as the opinion of the parent or (adolescent) patient are used. From these opinions it should be derived whether the patient has benefited sufficiently, and whether the termination was in agreement of both the therapist and the patient.

Last, we did not include articles on methods and strategies to reduce dropout and enhance therapy attendance and adherence in our meta-analytic review and literature review, while much work has already been done in this area. We thus recommend a focus on studies that analyze methods and strategies to reduce dropout in the future. Several authors have already reviewed the studies on strategies for reducing dropout in psychotherapy with children, which all focused on enhancing therapy engagement of the parents or of the whole family (Gopalan et al., 2010; McKay & Bannon Jr., 2004; Morrissey-Kane & Prinz, 1999; Nock & Ferriter, 2005). As far as we know, this has not yet been done for adolescents though.

### **Implications and recommendations for clinical practice**

The results of the studies in this thesis indicate there is still a lot to be done to increase our knowledge on the ethnic differences in the pathways to YMHC, and the processes within YMHC. As this thesis focused specifically on the children and adolescents within YMHC, this will be the main focus of our implications and recommendations. Recommendations for professionals working in institutions on the pathway to YMHC, or for the parents and potential patients themselves, are beyond the scope of this thesis.

First, because children and adolescents of all ethnic minority groups and adolescents of native Dutch descent tend to underutilize YMHC, it is important for YMHC institutions to reflect on measures to become more accessible for youth in general and for ethnic minority children in particular. This can for instance be done by intensifying the relationship with referral agents and institutions (e.g., youth care, school, GP's), and by increasing the knowledge on the recognition of disorders and the possibilities of YMHC with the potential patients (e.g., information sessions at places where parents and youth often come). A complicating factor is that at this moment there is a change in how YMHC is arranged and financed in The Netherlands (i.e. the 'transition' will make child mental health the responsibility of the local authorities) (Pijpers et al., 2013; R.R.J.M. Vermeiren, 2013). The goal is to switch focus from psychiatric treatment to regular youth care and upbringing problems, with less money being available for YMHC. Because of

drastic budget cuts, even more youth may not access the needed psychiatric treatment. It is at present unknown how this may affect differences between ethnic groups.

Second, with respect to the diagnostic process, it is helpful to gain insight in the cultural background of the patient and his family. For this purpose, the DSM offers an adaptive interview technique (the Cultural Formulation Interview) (APA, 2013; Kirmayer et al., 2008) These cultural formulations provide additional information, e.g. on the client's life context, identity, explanatory models and meaning. Assessing a client's worldview through such interviews, or how the client views the world from social, ethical, moral, and philosophical perspectives, is necessary to comprehensive, culturally sensitive assessment (Lonner & Ibrahim, 2002). When making decisions on a certain diagnosis, it is important to refer to the potential limited usefulness of the questionnaires in the diagnostic process, and to make sure that other professionals that are going to work with the patient are aware of these limitations (i.e., the diagnostic classification might have to be changed after renewed insight) (De Jong & Van Ommeren, 2002; Van de Vijver, 2011).

Third, an ethnic match between therapist and the parent or the adolescent patient might increase the chance that patients will complete therapy, and mental health institutions might thus try to ethnically match their patients and clinicians. Although in the Netherlands it was shown that the majority of adult Turkish and Moroccan patients did not value ethnic matching as important; clinical competence and compassion were considered to be more relevant than ethnic background (Knipscheer & Kleber, 2004).

Fourth, clinicians should be aware of the therapeutic alliance; a negative or decreasing quality of the therapeutic alliance can increase the dropout risk (and this accounts for patients of various ethnic backgrounds). It is recommended that the therapist should communicate it with the patient (i.e., give feedback) if there is a drop in the rated quality of the therapeutic relationship. It is probable that giving feedback to the patient about the course of the therapeutic relationship will lead to an improvement in this relationship, and will then lead to a decrease in dropout and an increase in completion of therapy. For instance, the (C-)SRS (Child Session Rating Scale) (B.L.; Duncan et al., 2003; S. D. Miller & Duncan, 2004; S. D. Miller et al., 2006) can be a very useful measure for evaluating the therapeutic relationship during therapy.

