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Where's the need? the use of specialist mental health services in adolescence and young adulthood

Raven, Dennis

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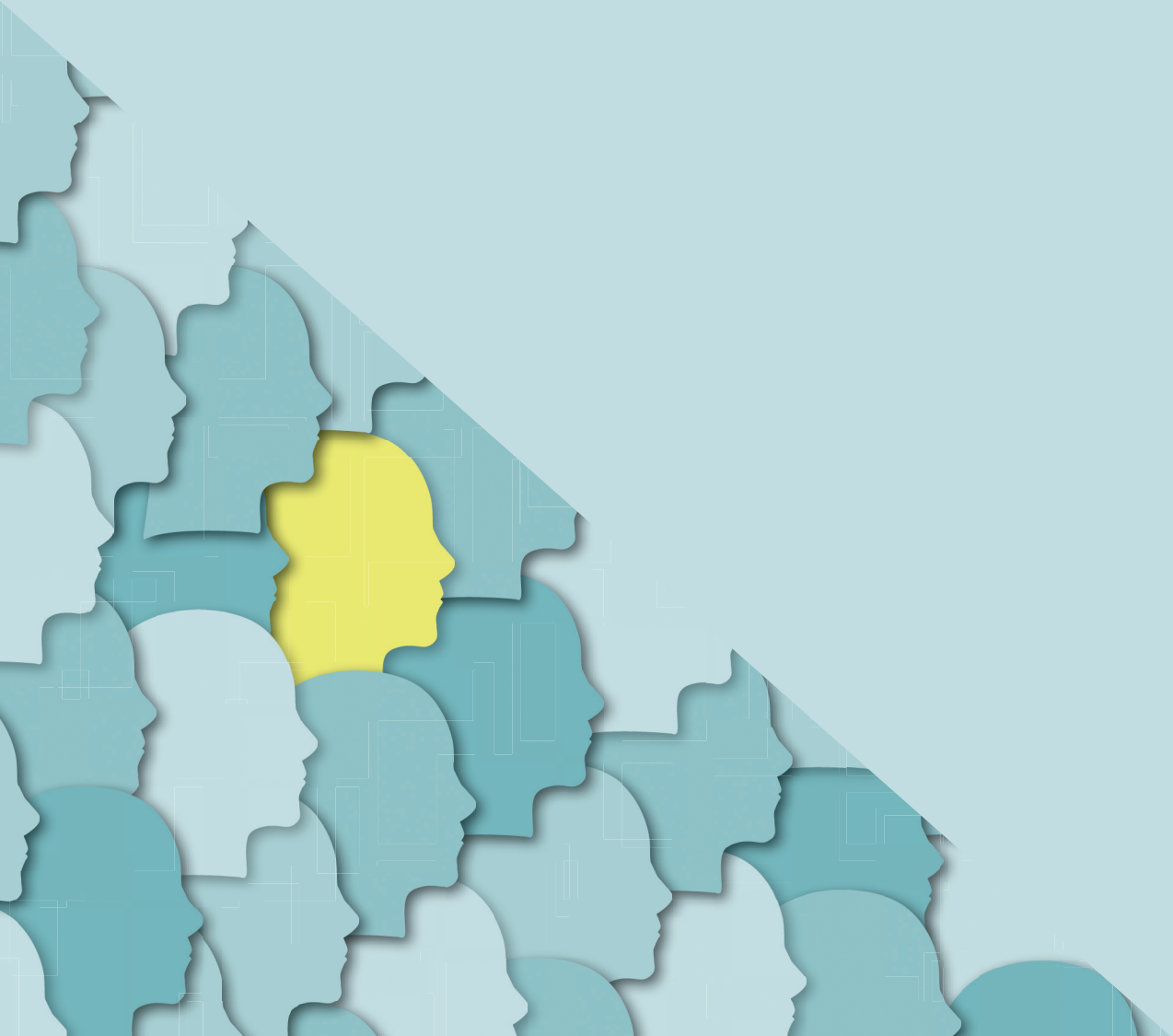
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General discussion



The overall aim of this thesis was to further understand the treatment gap in adolescence. This thesis covered three topics: (1) mental health in adolescence (chapters 2 and 3), (2) mental health care use in adolescence and young adulthood (chapters 4, 5, and 6), and (3) adolescents with a need for care not in mental health care (chapters 7 and 8). In this chapter, the main findings from the previous chapters will be briefly summarized. Subsequently, these findings and their interconnectedness will be discussed in a broader context. Finally, the main limitations of the studies reported in this thesis will be addressed, and some clinical implications will be put forward.

9.1 Summary of study findings

In chapter 2 we investigated the epidemiology of mental disorders in adolescence. We found a lifetime prevalence of any mental disorder at age 19 of 45%, half of which was associated with severe impairment or distress. Anxiety disorders were most prevalent, followed by mood disorders, behavior disorders, and substance dependence. Attention deficit hyperactivity disorder and phobias typically had the earliest age of onset, followed by oppositional defiant disorder and conduct disorder, other anxiety disorders such as generalized anxiety disorder and obsessive-compulsive disorder, mood disorders, most often major depressive disorder, and substance dependence. Mental disorders were quite persistent, indicating homotypic continuity, and also predicted the onset of disorders from other diagnostic groups, indicating heterotypic continuity. Finally, we found substantial co-morbidity, illustrated most by the fact that one quarter of all lifetime disorders and one third of all severe lifetime disorders concentrated in only 5% of the sample.

In chapter 3 we compared clinical diagnoses established by a mental health care professional with independently obtained diagnoses based on a fully-structured lay administered diagnostic interview in a subsample of adolescents who were referred to specialist mental health care. We found limited concordance between diagnoses from both sources. Only about 1 in 3 adolescents with a mood or anxiety disorder according to the diagnostic interview had a clinical diagnosis from the same diagnostic group. For behavior disorders, this rate was about 2 in 3 adolescents. About 2 in 5 adolescents had a clinical diagnosis that was not covered by the standardized diagnostic interview.

In chapter 4 we described the time-to-treatment of common mental disorders and its correlates for contact with any health care professional and specialist mental health care separately. Overall, almost half of the adolescents with a mental disorder had not had contact with a health care professional regarding their disorder by age 19. The time between the onset of a mental disorder and first contact with a health care professional varied considerably across disorders. It was shortest for mood disorders, although still less than 50% of adolescents with a mood disorder had been in contact with a health care

professional within two years after its onset. The time-to-treatment was typically shorter for disorders a) that manifested later in adolescence; b) that were associated with more severe levels of impairment or distress; and c) that were followed by the onset of a co-morbid mood disorder. These findings were largely replicated for specialist mental health care use.

In chapter 5 we investigated the relative importance of adolescents' own perception of their behavioral and emotional problems and the perceptions of their parents and their teachers for first contact with specialist mental health care between age 9 and age 21. We found that internalizing problems, but not externalizing problems, predicted the first contact with specialist mental health care services. Furthermore, we found that teachers' perceptions are the driving force behind first contact with specialist mental health care services from age 11 to age 13, parents' perceptions from age 13 to age 16, and the adolescents' own perceptions from age 16 onward.

In chapter 6 we described the treatment gap during the transition from adolescence to adulthood, covering age 16 to age 25, and related it to the "*big five*" markers of adulthood; living independently, completing an education, getting employed, having a stable relationship, and having children. Specialist mental health care use showed a continuous increase throughout the transition period, although the treatment gap remained large. The increase was stronger for women than for men. Of the markers of adulthood, living independently increased whereas being in a stable relationship decreased the chance of service use.

In chapter 7 we focused on the clinical trajectories of emotional and behavioral problems in treated and untreated adolescents. Subsequently, in those adolescents who received treatment in a specialist mental health care setting, we investigated the existence of a dose-response relationship; i.e. whether an increase in the number of treatment sessions predicted a decrease of emotional and behavioral problems. We selected a subsample of adolescents with clinical levels of self- or parent-reported problem behavior, and compared those with first specialist mental health care use between age 13.5 and age 16 to those without any mental health care use. We found that adolescents in specialist mental health care had higher levels of emotional and behavioral problems during the study period than untreated adolescents, and more often had a (severe) mental disorder at age 19. However, we found no difference in the course of emotional and behavioral problems during the years prior to treatment compared to the course of emotional and behavioral problems in untreated adolescents over the same period. We also found no evidence of a dose-response relationship in adolescents who used specialist mental health care services.

In chapter 8 we aimed to describe remission of untreated depressive and anxiety problems in adolescents and young adults with a need for care, and to assess the extent to which mental health problems recurred after untreated remission. Of the adolescents and

young adults who reported clinical levels of mood or anxiety problems, almost 80% did not report clinical levels anymore at follow-up some two to three years later. Nevertheless, 15% to 35% still reported subclinical levels, thus indicating partial remission. During any follow-up after (partial) remission, 5% to 40% reported clinical levels again, indicating relapse, and 25% to 50% reported specialist mental health care use in future assessment waves.

9.2 Mental health in adolescence

In chapter 2, we found a lifetime prevalence of any mental disorder at age 19 of 45%. This is highly comparable to lifetime prevalence rates reported in studies using similar methodologies from New Zealand (Fergusson & Horwood 2001) and the US (Merikangas *et al.* 2010a). Results from studies using a prospective study design suggest that the prevalence of mental disorders may actually be much higher than studies using a cross-sectional design. Moffitt and colleagues (2010) showed that their prospective study design yielded prevalence rates that are twice as high as those reported in cross-sectional studies. Copeland and colleagues (2011) reported a cumulative lifetime prevalence rate of any disorder of no less than 82.5%, which is indeed almost twice as high as the prevalence rate we found. Furthermore, Angst and colleagues (2016) reported a cumulative prevalence rate of any mental disorder of 73.9% in their prospective study covering age 20 to 50. Based on the results from prospective studies, they conclude that emotional and behavioral problems are nearly universal in nature. One would thus expect that almost everyone will be faced with emotional or behavioral problems at some point in their lives.

In all there is much support for the conclusion that mental health problems are highly prevalent in adolescence. The significance of this finding is not so much in its absolute value, however, but much more in its consequences. We showed considerable homotypic and heterotypic continuity of mental disorders up until age 19. Other studies showed that disorders with an onset in childhood or adolescence are predictive of disorders in adulthood (Kim-Cohen *et al.* 2003; Copeland *et al.* 2009; Kessler *et al.* 2012a), and that approximately half of all cases will have developed their first mental disorder by the age of 14, and about three quarters by the age of 24 (Kessler *et al.* 2005a, 2007a, 2007b). Based on this literature, we would expect that mental disorders established at age 19 are highly predictive of mental disorders later in life. Next to consequences for mental health, the impact of mental health on actual functioning is important for assessing the significance of our findings. In a study using TRAILS data, the adverse effects of mental disorders on functional outcomes in early adulthood, such as low educational attainment and suicidal ideation, have already been shown (Ormel *et al.* 2017). It would be very valuable to extend TRAILS with a follow-up diagnostic interview as well as future assessments of functioning,

to determine the significance of mental ill-health in adolescence for the transition to adulthood.

Two other specific findings regarding mental health in adolescence are worth mentioning. First, mental disorders with a late age of onset seem to be more often associated with severe impairment or distress than disorders with an onset earlier in life. Such an association could be explained by the same mechanism that underlies the increased vulnerability for developing a mental disorder in adolescence. As demands on adolescents increase over time, the inability to meet those demands creates stresses that are increasingly difficult to cope with, in turn increasing levels of impairment and distress. One could also imagine that newly developed symptoms cause higher levels of perceived distress because they reflect an acute change, compared to older symptoms with which one is more familiar and accustomed to.

A second finding worth mentioning is that mental disorders tend to concentrate in a small group of adolescents. As we showed, a small group of adolescents consisting of only 5% of our sample accounted for a quarter of the lifetime, past year, and past month disorders, as well as one third of all severe lifetime disorders. As a result of the homotypic and heterotypic continuity as well as increasingly falling behind on many domains of adolescent and future adult functioning, this group of adolescents is very vulnerable. This strong concentration of disorders may point to an underlying vulnerability for developing mental disorders, such as the P factor dimension as proposed by Caspi and colleagues (Caspi *et al.* 2014). Efforts are required to identify such adolescents and intervene at an early stage.

9.3 Mental health care use in adolescence

In this thesis, we addressed the use of mental health services in multiple chapters. One interesting finding is that at age 19, almost half of all adolescents with a mental disorder had been in contact with a health care professional, which is a relatively large proportion compared to findings from other studies (Merikangas *et al.* 2011; Jörg *et al.* 2016). We defined the term health care professional very broadly, however, which probably contributed to the high treatment rate we found. We included not only general practitioners, psychologists and psychiatrists, but also clergymen, herbalists, and acupuncturists. Although we do not know which professional was actually contacted, it is fair to assume that this latter group contributed only marginally to the overall rate of service use. Another contributing factor to explain the high treatment rate may be that the adolescents were only asked whether they had ever talked to a health care professional about their symptoms. Talking about symptoms does not imply that the adolescents actually received some form of treatment at all, or, in case they did, that the treatment was effective.

From the use of any service we can zoom in on the use of specialist mental health care. Also in chapter 4 we found that just over one quarter of the adolescents with a mental disorder had been in contact with specialist mental health care. This rate is low compared to other studies (Ford 2008). The most likely explanation for this is that we excluded adolescents with an onset of any mental disorder before January 2000, when study participants were roughly nine years old. Supporting evidence for this explanation comes from a study by Jörg and colleagues (2016) in which the same TRAILS data were used without excluding adolescents with early-onset disorders. They reported that approximately one third of adolescents with a mental disorder had received specialist mental health care (Jörg *et al.* 2016), which is similar to findings from other studies (Ford 2008).

While in chapter 4 we used administrative data to assess specialist mental health care use, in chapter 6 we used parent- and self-reported data. There, we found that the treatment rate of adolescents with clinical levels of self-reported emotional or behavioral problems increased from 11% at age 16 to 33% at age 25. Especially the treatment rate at age 16 is likely to be underreported, however, probably because the parent's view on the adolescents' mental health problems was not included. At ages 16 and 19, the treatment rates we found (5.4% and 7.1% respectively) were slightly lower than those reported by Reijneveld and colleagues (2014) (5.6% and 7.4% respectively), probably due to study attrition at ages 22 and 25. Nevertheless, the increase of the treatment rate among adolescents with clinical levels of self-reported mental health problems does match the increased influence of adolescents on their own service use as shown in chapter 5.

Although treatment rates by themselves are important indicators of how adolescents fare, they do not tell us much about actual treatment. Adolescents who do make contact with specialist mental health care may not be treated for the disorder that caused them to seek help. In chapter 4, we found that lifetime treatment rates in specialist mental health care of adolescents with a mood disorder was relatively low; whereas almost 65% reported treatment contact with any health care professional, only 35% had been in contact with specialist mental health care. This appears to be in contradiction with our findings from chapters 5 and 6, where we found that specialist mental health care use in adolescence is driven by internalizing problems rather than by externalizing problems. However, our findings from chapter 3 may shed light on this apparent contradiction. There, we showed that adolescents in specialist mental health care often did not receive a clinical diagnosis from the same diagnostic group as the research diagnosis according to the diagnostic interview. This difference was especially profound for mood and anxiety disorders. Together, these findings suggest that the mental health problems that trigger help-seeking may not be the same mental health problems as those that are treated by the clinician. This can be explained by the developmental pattern of mental disorders as established

in chapter 2. The presence of a mental disorder increases the risk of developing additional mental disorders. As also discussed in chapter 4, throughout adolescence the demands placed on the adolescents change. Adolescents may have developed coping strategies to deal with their symptoms, but these may not be adequate to meet these new demands and to keep functioning appropriately. This may in turn cause new symptoms to develop, or existing symptoms to deteriorate, which further increases functional impairment and distress. When the adolescents finally seek help, they may receive treatment for the source symptoms rather than for the newly developed, co-morbid symptoms. In case of chapter 5, the age range that was covered, from age 11 to age 21, coincides almost perfectly with the age range during which mood disorders have the highest incidence rate. Hence, while incident emotional problems may trigger service use, other underlying problems may be the focus of clinical intervention.

Overall, these results suggest that between one in four and one in three adolescents and young adults with mental health care problems have been in contact with specialist mental health services. A pattern emerges of an accelerated increase of specialist mental health care use during late adolescence and early adulthood, driven by the development of internalizing mental health problems during this period. These internalizing problems are often mood disorders, in particular depression. Once having entered into the health care system, health care professionals may diagnose and treat the underlying disorders with an onset in childhood or early adolescence that preceded the mood disorders.

9.4 Adolescents with a need for care not using services

As we have shown, mental health problems are common in adolescence and young adulthood, yet a substantial share of those with mental health problems do not use specialist mental health services. This may be interpreted as unmet need for care (Aoun *et al.* 2004). How these adolescents fare was discussed in chapters 7 and 8.

The vast majority of adolescents with such an unmet need for care did not report clinical levels of mental health problems at follow-up two to three years later, indicating untreated remission. In general, a depressive episode is likely to remit within a couple of months (van Straten *et al.* 2010), and untreated remission of depression has been found to be more common in childhood and adolescence than in adulthood (Whiteford *et al.* 2013b). However, the absence of clinically relevant levels of mental health problems at follow-up does not imply full nor lasting recovery. At follow-up, a proportion of adolescents often still reported sub-clinical levels of mental health problems, which are a known cause of substantial impairment (Roberts *et al.* 2015). Furthermore, many adolescents who remitted without using mental health care reported clinical levels of mental health problems or the use of mental health services at subsequent assessment waves. This is in accordance with

our conclusion from chapter 2 that most mental disorders are typically recurrent rather than chronic. This recurrent nature may also further explain why the time-to-treatment is often so long; if impairing symptoms keep on returning, adolescents are increasingly likely to seek help, especially since their environments are becoming increasingly demanding.

Next to substantial unmet need for care, the results presented in this thesis thus also show some indications that a part of adolescents with unmet need for care are likely to find their way into specialist mental health care. Studies using adult samples showed that in rare cases it may even take several decades after onset until initial contact with mental health care (Wang *et al.* 2004, 2005). However, our findings from chapter 7 immediately raise the question of how much children and adolescents benefit from treatment. We did not find evidence that adolescents improved following the use of specialist mental health care, which is in line with findings from other naturalistic studies (Zwaanswijk *et al.* 2006; Jörg *et al.* 2012; Patton *et al.* 2014; Nilsen *et al.* 2015). Interestingly, remission and recurrence patterns found in treated adolescents (Curry *et al.* 2011) are remarkably similar to those we found in adolescents with untreated mental health problems. We do need to tread carefully, however, as we had a naturalistic study design and knew very little about the treatment that the individual adolescents actually received. There are many methodological reasons that can potentially explain why we did not find a treatment effect (c.f. Jörg *et al.* 2012). This by itself calls for very modest conclusions and a firm recommendation to undertake naturalistic studies to investigate the effect of treatment in child and adolescent mental health care in the real world.

However, the literature does show that adolescents can benefit from treatment. For instance, evidence-based treatment in child and adolescent mental health care has been found to be more effective than treatment as usual (Weisz *et al.* 2006). This may indicate that these evidence-based treatments have not yet, or not effectively, been implemented in clinical practice. An alternative explanation may be that treatment is effective at attaining remission, but not at preventing relapse. This is in line with a review by Cox and colleagues (2012), who concluded that it is unclear which treatment is most effective at preventing relapse in children and adolescents with depression. Thus, before being able to draw definitive conclusions, more research on the implementation of evidence-based treatments and on relapse prevention are direly needed.

9.5 Predictors according to the behavioral model of health services use

It is valuable to look at the results discussed in this thesis from the perspective of theoretical models underlying mental health care use. We have chosen the *behavioral model of health services use* developed by Andersen (1968, 1995) as the stepping-stone, as it is a theoretical

model that lends itself well for practical application in health services research. The behavioral model mainly focuses on explaining service use by the means of predisposing, enabling and need factors. The studies in this thesis covered a substantial part of the model. Next, we will discuss the most relevant predictors that we included in our analyses.

Of the predisposing factors, *sex* and *age* were most important. Our findings that males use mental health care more often than females in early adolescence, but are gradually overtaken by females from middle adolescence onwards are consistent with the literature (Zwaanswijk *et al.* 2003; Sayal 2006; Ford 2008; Reijneveld *et al.* 2014).

Ethnicity was no important predisposing factor in our studies. This could be interpreted as a positive sign, as apparently access to the Dutch health care system does not depend on the ethnic background of adolescents. Caution is warranted when interpreting this finding, however, as evidence from the literature is highly contradictory (Zwaanswijk *et al.* 2003; Sayal 2006; Ford 2008; Babitsch *et al.* 2012). In a recent Dutch study, which included children from a particular part of the city of Rotterdam of whom two third of non-Dutch ethnicity, mental health care use was shown to be less likely among ethnic minority children than among Dutch children (Bevaart *et al.* 2014). Our results from chapters 4 and 6 showed a trend in the same direction, but the effect were not statistically significant. As adolescents from an ethnic minority background were underrepresented in TRAILS (Ormel *et al.* 2015), we may not have had sufficient power to detect differences that do exist in the population. However, as Ford noted in her review, it is very difficult to appraise and compare findings related to ethnicity between studies, as due to the "*complex interaction of culture, history, geography and race that make up ethnicity, [. . .] any influence of ethnic minority status on health and access to health care is unlikely to be the same for different ethnic groups in different locations at different times*" (Ford 2008, p. 908).

Parental separation was a predisposing factor that did prove important in multiple studies presented in this thesis. Adolescents whose parents had separated were more likely to use specialist mental health care than adolescents whose parents were still together, which has been found in other studies before (Zwaanswijk *et al.* 2005b; Sayal 2006; Ford 2008). Parental separation is often seen as a process of stressful events, and has been associated with child emotional and behavioral problems (Amato 2000). The fact that children from separated parents find their way into the health care system can be interpreted positively, as therapeutic interventions have been shown to protect such children from poor outcomes (Amato 2000). One would expect, however, that such interventions are offered as a part of youth social care rather than child and adolescent mental health care (c.f. Reijneveld *et al.* 2014). An association between parental divorce and specialist mental health care use therefore points at substantial mental health risks above and beyond the risks that are addressed in therapeutic interventions aimed at protecting children from the adverse effects of their parents' divorce. Especially considering

the increase in the rate of divorce over the past decades, the mental health of children from divorced parents is an important public health concern.

The last of the predisposing factors that was extensively covered in this thesis regards *socioeconomic background*. In chapters 4 and 5 we found that being from a low or middle socioeconomic background was associated with higher rates of incident specialist mental health care use compared to being from a high socioeconomic background. In chapter 6, however, we did not find an association between socioeconomic background and specialist mental health care use. Neither did Reijneveld and colleagues (2014), who covered service use between ages 11 and 19, and to whose study chapter 6 was a follow-up. There are differences between the studies from chapters 4 and 5 and those from chapter 6 and Reijneveld and colleagues (2014), however. In chapters 4 and 5 initial specialist mental health care use was predicted using administrative data of specialist mental health services, whereas in chapter 6 and the study by Reijneveld and colleagues (2014) all use of specialist mental health care was predicted using parent- and self-reports. These differences leave two avenues to explain these seemingly contradictory findings. First, parent- and self-reported service use included private practices, whereas the administrative data did not. Parents from a high socioeconomic background may prefer to send their children to small private practices rather than typically large institutions. Second, socioeconomic background was associated with any use of specialist mental health services, but not with incident use. This suggests that parents from a high socioeconomic background tend to send their children to specialist mental health care earlier than parents from a low socioeconomic background. Some support for this explanation can be found in another TRAILS study, in which it was shown that specialist mental health care use was actually higher in adolescents from a high compared to adolescents from a low socioeconomic background (Amone-P'Olak *et al.* 2010). This study covered specialist mental health care use between the first two assessment waves, roughly between the ages 11 and 14. Parents from a high socioeconomic background may be better able to recognize mental health problems in their children at early stages, or to persuade their general practitioner to refer them to specialist care than parents from a low socioeconomic background. In all, both of these explanations leave room for at least a small degree of socioeconomic differences in access to mental health care for adolescents.

Enabling factors were hardly covered in this thesis. An important reason for this is that many enabling factors, such as the availability, accessibility, affordability, and acceptability of services (Stiffman *et al.* 2004), are assessed predominantly at the community level. At personal level, enabling factors such as *education* and *income* may not be adequate predictors in adolescence and early adulthood, as participants' achieved levels of education and income often do not reflect their true potential. Furthermore, other influential factors

like *personal competences* and *social support* were not consistently assessed throughout the TRAILS study, and were therefore not included.

Need factors were addressed throughout this thesis. The *need for care* was typically operationalized as mental health problems reported by participants, their parents, or their teachers. The general conclusion that mental health problems predict specialist mental health care use is all too obvious, however, and far from being a novelty. We did present a number of interesting findings that have not been reported before, however, such as the shift from teacher to parent to adolescent as the driving force behind initial specialist mental health care use in adolescence, and the typically long time it takes to seek help after the onset of a mental disorder.

Need for care is highly predictive of service use, but the strength of this association appears at odds with the treatment gap that we reported in chapters 4 and 6, and has been consistently reported in the literature (Angold *et al.* 2002; Vanheusden *et al.* 2008a; Merikangas *et al.* 2011; Jörg *et al.* 2016). The behavioral model of health services use lays bare an important caveat in the way need for care was operationalized in this thesis, and in many other epidemiological studies (Regier *et al.* 1998; Aoun *et al.* 2004). The measures we used, such as the youth self-report (YSR) and adult self-report (ASR), typically assess the presence of symptoms, but neglect the extent to which these symptoms are perceived as requiring help. Despite the explicit inclusion of impairment criteria, illness perception is also not incorporated in the diagnostic interview. Therefore, these instruments tap into illness awareness at best. Awareness is only a first stage in the help-seeking process, however. Subsequently, problems need to be recognized as severe enough to require treatment. In the case of children and adolescents, others such as parents and teachers also play a crucial role in this process (Logan & King 2001; Stiffman *et al.* 2004), as we also showed in chapter 5. Although the perception of need is thus a very important aspect of need for care, the treatment gap cannot be explained by the use of measures that do not incorporate such a perception. For instance, in a previous study using TRAILS data, Jansen and colleagues (2013) showed that only approximately one third of adolescents whose parents reported a perceived need for treatment actually received treatment. This suggests that additional factors, such as those covering a larger part of the help-seeking process, need to be included when trying to explain service use (Logan & King 2001; Stiffman *et al.* 2004).

One important additional issue that needs to be addressed is that many predictors of mental health service use are also associated with mental (ill)health. For instance, parental divorce creates stresses that increase the child's risk of developing emotional and behavioral problems (Amato 2000). However, parental divorce is also associated with increased service use (Sayal 2006), which can be explained by an increased perception of a need for help, and increased reporting of child problem behavior by the parents, as well as an increased likelihood of referral (Verhulst & van der Ende 1997). This issue is

particularly important for community-based studies in which service users are compared to non-service users (Ford 2008), such as the studies presented in this thesis. We always included some measures of psychopathology in our analyses, but we cannot fully exclude the possibility of some residual confounding.

9.6 Alternative models focusing on health services use

Altogether, the behavioral model was a valuable model for structuring the findings reported in this thesis. It helped us to identify factors that are important when analyzing specialist mental health care use, but also showed which areas of interest were insufficiently covered. However, although the behavioral model is very well suited when studying the predictors of service use, it is worth reviewing our findings from the perspectives of two other well-known theoretical models: the pathway to psychiatric care model and the network-episode model.

The *pathway to psychiatric care model* by Goldberg & Huxley (1980, 1992) models the health care system from an hierarchical perspective, as a 5-level pyramid. Each step on the pathway is represented as a separate level, with filters in between representing the selection processes encountered when progressing up the hierarchy. Psychopathology in the community is at the bottom of the pyramid, and is best captured in chapter 2 of this thesis. Mental health care use, the primary focus of this thesis, is represented at the top of the pyramid, at levels 4 (outpatient services) and 5 (inpatient services). From this perspective it is immediately apparent that the levels in-between the community and specialist mental health care largely remain a black box in the studies presented in this thesis. It is precisely these steps, however, that often have to be taken before being able to enter into specialist mental health care, for instance due to the gatekeeper role of the general practitioner in the Dutch health care system.

The question is therefore to what extent our findings are biased because of this black box. We know that the majority of cases with a mental disorder do not seek help, and thus fail to pass even the first filter on the pathway to care. From chapter 4 we can gather that these are primarily adolescents with a single mild mental disorder, who probably had an onset early in life. If a mental disorder develops from a mild into a more severe disorder, or if co-morbid disorders develop, the likelihood of entering into the health care system increases. The most severe cases will subsequently be referred to mental health care, and will be identified as users of mental health care in our studies. Eventually, only a fraction of the cases who are identified in the general population as having a mental disorder pass through the first filters, which include recognition by one self or one's parents, and recognition and referral by the general practitioner. In The Netherlands, approximately 20% of children and adolescents with mental health problems recognized by their general

practitioner were referred to specialist mental health care in 2008 (Zwaanswijk *et al.* 2011). Most cases with common mental disorders will never reach specialist mental health care. From this point of view the value of psychiatric case registers, such as the Psychiatric Case Register North Netherlands, for research on common mental disorders has been questioned (Munk-Jørgensen *et al.* 2014).

Our results indeed show that adolescents often do not receive specialist mental health care for their disorders. That does not necessarily mean, however, that the results we presented in this thesis lose value because of adolescents who were obscured from our sight in the black box of first line health services. The first indication to support the value of our results is that no less than one quarter of the adolescents in our sample were identified in the psychiatric case register. More specifically, over one third of adolescents with at least one mental disorder were identified (Jörg *et al.* 2016). These are much higher proportions than would be expected based on the pathway to psychiatric care model (Goldberg & Huxley 1980; Munk-Jørgensen *et al.* 2014). The second indication is that the gatekeeper role of the general practitioner in The Netherlands has been relaxed for children and adolescents as the Youth Care Office and preventive youth care also offer ways into the health care system. Zwaanswijk and colleagues (2005a) showed that in The Netherlands, the role of the general practitioner in providing children and their parents access into mental health care was limited. The majority of children with a need for care reached mental health care either directly, a route sometimes referred to as "*the American bypass*" (Goldberg & Huxley 1980), or through other service providers, most often school-based. These patterns were also observed in TRAILS; the vast majority of adolescents who used specialist mental health services reported having consulted their general practitioner, but school-based services were also often used (Jörg *et al.* 2016). This is in line with results from chapter 4, which suggest that approximately half of the adolescents who sought help for their disorders had entered into specialist care by age 19. Based on these indications, we conclude that we may have missed a sizeable number of adolescents who entered into primary care but not specialist care. Hence, including primary care would have increased the value of our research. However, we did capture a number of adolescents in specialist mental health care sizeable enough to provide substantial value to our findings.

Another theoretical model worth examining is the *Network-Episode Model* developed by Pescosolido (1991, 1992, 2006). This model was developed as a response to one of the main limitations of the behavioral model, namely that it mainly revolves around an individual's access to services (Munson *et al.* 2012). This limitation is illustrated by the fact that the behavioral model typically only explains approximately 20% of the variance of service use (Stiffman *et al.* 2004). The Network-Episode Model focusses on the interplay between the dynamic processes of how individuals respond to health problems during the entire course of an illness, the "*illness career*", and the social network in which the individual

is embedded. Both aspects are especially relevant when examining mental health care use among adolescents, but are less pronounced in the behavioral model.

The illness career is reflected most notably in chapters 2 and 7. In chapter 2, we described the sequence in which mental disorders develop by showing that mental disorders that develop over the course of adolescence are often preceded by mental disorders that developed earlier in adolescence or childhood. In chapter 7 we showed how mental (ill)health can fluctuate over time. Therefore, the need for care is not a constant that may trigger service use, as might be concluded from the behavioral model, but rather varies over the illness career. From this perspective, our finding from chapter 4 that it often takes many years before adolescents seek help for their mental disorders may be more plausible than initially thought from the perspective of the behavioral model.

The way adolescents are embedded in their social network is also not easily recognizable in the behavioral model. The social network is important for everyone, but in particular for adolescents, as they are highly dependent on others for access to care. As we showed in chapter 5, which actors from the social network drive entry into specialist mental health care during adolescence shifts over time, from teachers to parents to eventually the adolescents themselves. Considering the importance of the social network and its social support system, it is highly likely that peers, and later romantic partners, also play an important role in the dynamics that may culminate in mental health service use. The social network was included in our studies only to a limited extent; we focused in particular on the role of parents and teachers.

The role of first line services, the illness career and the social network are all aspects that are incorporated into the behavioral model, albeit not explicitly. The role of the general practitioner can be interpreted as part of the evaluated need for care. The social structure is referred to as a predisposing factor by Andersen (1995), while the social support that one actually received is considered an enabling factor (Andersen *et al.* 2013). The concept of the illness career is somewhat more difficult to recognize in the behavioral model, but can perhaps best be interpreted as the iterative processes between need, health behavior, and outcomes. Overall, one of the great strengths of the behavioral model is its apparent simplicity, but it is this perception of simplicity that is perhaps its most deceptive feature.

9.7 Strengths and limitations

The studies presented in this thesis all have their strengths and weaknesses, which were addressed in each chapter separately. However, when discussing the findings of these studies from an aggregated perspective, it is also valuable to assess the overarching strengths and limitations. Below, the strengths and limitations of the most prominent features of the data that were used in this thesis are discussed.

The first key feature regards the use of TRAILS data, upon which all studies presented in this thesis were based. In TRAILS, a cohort of youngsters was followed from pre-adolescence to young adulthood, with assessment waves two to three years apart. To date, TRAILS data have been used in over 300 international, peer reviewed publications, which is a testimony to the quality of the study. This thesis benefitted from many of TRAILS' key features, such as its high inclusion (de Winter *et al.* 2005) and retention rates (Nederhof *et al.* 2012), its highly multidisciplinary scope, which resulted in a very wide range of data being available (Oldehinkel *et al.* 2015), and its long follow-up time, which covered age 10 to age 26. The TRAILS data were not collected specifically for the aims of this thesis, however. As a result, it was not always possible to include all measures one would ideally have available. Regarding the need for care, measures covering perceived need and coping would have been excellent additions. The same goes for measures related to health beliefs, such as the stigma surrounding mental health, and personal competences. The pathway to psychiatric care could have been explored into more detail with the inclusion of more information regarding the use of school-based services and the general practitioner. The importance of the social network could have been reflected in the inclusion of measures assessing need based on reports by a best friend or romantic partner. Furthermore, information about the treatment that was received, such as type, length and outcome, would also have made a valuable addition. However, the costs and time involved in collecting such data should also be taken into consideration. Overall, the contribution of the TRAILS data to this thesis has been much more valuable than newly collected data reasonably ever could have been.

A second key feature regards the use of administrative data of specialist mental health care use. Adolescents (and their parents) were asked for consent to link their TRAILS data to the Psychiatric Case Register North Netherlands (PCRNN), which contains information about the use of specialist mental health care services and clinical diagnoses. The PCRNN covered a geographical region and time period that largely overlapped with TRAILS. Although the use of administrative data is a major strength, it was also associated with some limitations. First, almost 25% of the TRAILS participants could not be included because there was no consent for linking their TRAILS data with the administrative data, due to either attrition or refusal. Although participants who did consent did not differ from those who refused or whose consent was missing with regard to parent-reported specialist mental health care use at the first three assessment waves, it cannot be ruled out that this did introduce bias into the final sample we used. Second, administrative data were available from January 2000 to December 2011, which corresponds roughly to the period between the first and fifth assessment waves in TRAILS. Data were not available from before 2000 (about the age of nine) and after 2011 (about the age of 22). Furthermore, the coverage was also limited with regard to geographic location; the data covered Groningen, Friesland and Drenthe, the three northern provinces of The Netherlands, but not the rest of The Netherlands.

This posed a growing problem as the adolescents got increasingly mobile as they grew older; at the fifth assessment wave (about the age of 22), some 13% of the participants had moved to a part of The Netherlands that was not covered by the PCRNN. The data also did not cover private practices and commercial institutions; which accounted for about 25% of all mental health care trajectories in child and adolescent psychiatry in Groningen, Friesland and Drenthe (Jörg *et al.* 2016). Similarly, addiction care was not included. Finally, the administrative data did not contain any details about the kind of treatment that was received. It may even be that some adolescents who were identified in the PCRNN did not receive any treatment at all. For instance, medical guidelines state that a suspected mental disorder is enough to warrant referral to specialist mental health care (Nederlands Huisartsen Genootschap n.d.), and thus adolescents may be referred back to primary care if a mental disorder was not diagnosed in specialist mental health care.

The third key feature of this thesis is the use of the Composite International Diagnostic Interview (CIDI) to assess the presence of mental disorders. The CIDI was administered at the fourth assessment wave, when participants were 18 to 20 years old, and enabled us to describe the development of mental disorders in the first two decades of life. The use of the CIDI is a major strength over the use of only questionnaires, because the structured nature of the CIDI and the adherence to DSM-IV diagnostic criteria facilitate comparison of findings between different studies and translation to clinical practice. Reappraisal studies showed that CIDI diagnoses can generally be considered valid when compared to diagnoses obtained from blinded clinical interviews (Haro *et al.* 2006; Kessler *et al.* 2009), although the CIDI generally generates relatively high prevalence estimates compared to other diagnostic interviews (Brugha *et al.* 2001; Polanczyk *et al.* 2015). One limitation of the CIDI, and similar structured diagnostic interviews, is that diagnoses are not verified by mental health professionals. However, through the use of lay interviewers, administering the CIDI is considerable cheaper than administering a clinical interview, which opens up the possibility for use of diagnostic interviews in large epidemiological studies. A further limitation of the CIDI is that it provides little insight into how mental disorders develop within individuals. For instance, we were able to differentiate between mild and severe disorders, but we were unable to track when a disorder turned from mild to severe or vice versa. In addition, the CIDI does not easily allow for the identification of subthreshold disorders, which is a drawback because subthreshold disorders are associated with substantial burden (Roberts *et al.* 2015), and often develop into full syndrome disorders (Shankman *et al.* 2009). Recall bias is another limitation, as respondents may have forgotten about symptoms for which they did not seek help, and they may not remember correctly when particular events occurred. Finally, the CIDI covered only a selection of, typically more common, mental disorders. It did not cover schizophrenia and pervasive developmental

disorders, and personality disorders were disregarded because such disorders are typically not assessed in children and adolescents.

9.8 Implications for clinical practice and policy

The findings presented in this thesis have several implications. We found that almost half of all adolescents had developed a mental disorder by the age of 18, more than two thirds of which had developed their first disorder by the age of 12. Mental ill health in childhood and adolescence has a long-lasting impact, not only with regard to the continuity of mental health problems into adulthood, but also with regard to its detrimental effects on socioeconomic outcomes (Copeland *et al.* 2015b; Ormel *et al.* 2017). It is therefore of vital importance to address mental health problems as early as possible. Considering the difficulty of identifying mental health problems at young age, policy makers should put substantial effort into universal prevention programs. Prevention programs have been shown to be effective in reducing both future mental health problems as well as the detrimental effects on outcomes (Greenberg *et al.* 2001; Weissberg *et al.* 2003; Weisz *et al.* 2005; Merry *et al.* 2012). Ideally, policy makers should aim for long-term integrated universal prevention programs, which focus on protective factors as well as risk factors, such as poor parenting skills and children's maladaptive personality traits (Ormel *et al.* 2018), and which operate across multiple domains (Greenberg *et al.* 2001).

We also showed that many adolescents with mental health problems either do not receive treatment at all, or wait a long time before seeking help. Help-seeking was accelerated when co-morbid disorders developed. Since psychiatric history has been shown to adversely affect functional outcomes about as strongly as current mental disorders in late adolescence (Ormel *et al.* 2017), adolescents with mental health problems need to be identified as early as possible. Therefore, universal prevention programs should be supplemented by targeted prevention and early intervention programs aimed at those youths who are at high risk of developing or who already have developed mental health problems. Furthermore, considering that relapse of mental health problems is very common in adolescence, intervention programs should also include relapse prevention. Based on the currently available literature, we stress the importance of additional research into the effectiveness and implementation of such programs.

Based on our results, we recommend three focal points for prevention and intervention programs. The first should be aimed at schools, as school-based services have consistently been shown to be an effective point of entry into the health care system (Zwaanswijk *et al.* 2005a). Additionally, school-based intervention programs have been shown to be effective in reducing adolescents' mental health problems (Neil & Christensen 2009; Calear & Christensen 2010; Paulus *et al.* 2016). However, we found that from secondary education

onwards, teachers' ratings of adolescents' mental health problems became less decisive for entering into specialist mental health care. Therefore, programs should be developed that aim at improving the quality of the relationship between teachers and students and their parents.

The second focal point should be aimed at the family. Throughout this thesis, family-related factors were consistently associated with specialist mental health care use. Adverse family circumstances, such as a low socioeconomic position, parental separation, and a history of parental psychopathology were all associated with increased levels of specialist mental health care use. While this can be interpreted from a positive standpoint, that care is received by those who are most vulnerable, it also stresses the importance of looking out for these vulnerable families. Examples of potential intervention programs include offering information and education programs aimed at families from a low socioeconomic background, offering counseling aimed at the children for parents in divorce, and addressing the child's interest in the parent's treatment. Another important family-related factor is that child and adolescent mental health care use is associated with the burden perceived by the parents (Angold *et al.* 1998b; Sayal 2004; Ryan *et al.* 2015). Programs aimed at the family should therefore also focus on child and adolescent mental health problems that may not burden the parents enough to seek help, as these problems may develop into more serious problems later in life.

The third focal point should be aimed at mental health care professionals. Adolescents often have a history of mental health problems before they reach specialist mental health care, and the ones who do often show signs of co-morbid mental health problems. From our data we cannot tell whether clinicians actually explored and recognized these co-morbid problems, let alone whether they included them in their treatment plans. Clinicians should at least be very aware of the high probability that the adolescents they see do suffer from co-morbid disorders. The thoughtful implementation of standardized diagnostic assessments to uncover co-morbidity may help clinicians to tailor treatment plans to the specific needs of their adolescent clients. Such assessments have been suggested to improve the detection of emotional disorders (Reeves *et al.* 2016), which currently appear to be missed by clinicians relatively often.

9.9 Conclusion

Overall, we showed that mental health problems are highly prevalent in adolescence. Many adolescents do not receive timely treatment for their problems, and many do not receive treatment at all. Even adolescents who do enter into specialist mental health care may not be treated for all of their problems. Furthermore, mental health problems in adolescence are highly recurrent, also after treatment. Although specialist mental health

care use does increase between late adolescence and early adulthood, the treatment gap remains an important public health concern. Considering the difficulties in problem recognition, navigating the health care system, and receiving effective treatment, long-term integrated universal prevention and intervention programs are needed.

