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The Netherlands

## **Assessing the psychological distress and mental healthcare needs of unaccompanied refugee minors in the Netherlands**

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### **Citation**

Bean, T. (2006, October 19). *Assessing the psychological distress and mental healthcare needs of unaccompanied refugee minors in the Netherlands*. Retrieved from <https://hdl.handle.net/1887/4921>

Version: Not Applicable (or Unknown)

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**Note:** To cite this publication please use the final published version (if applicable).

# Chapter 1

## Introduction

Around the world, children and adolescents are exposed (directly or indirectly) to continuing organized violence and/or political unrest which affect their lives and development in a multitude of ways. In recent years, research in the behavioral sciences has attempted to unravel the intricate (biological, psychological, social, and cultural) pathways which lead to mental health or illness among refugee adolescents that have been exposed to organized violence in an array of different cultures. In this attempt, a limited amount of knowledge has been accumulated which has contributed to the development of interventions and treatments to strengthen emotional and social competencies of these young people who have experienced so much adversity.

Fortunately in the Netherlands, there have been numerous studies conducted among URM concerning their physical health (Van Willigen & Janssen, 2002; Broecheler & Raadgers, 2001), safety in reception centers (Dutch Inspection of Children and Youth Welfare Services, 2002), integration (Radstake & Dekovic, 2002; Smit, 1998; Snijders & van Wel, 1995) and legal rights (Kindercollectief, 2002; Cardol, 2005). However, epidemiological research regarding the mental health and/or mental healthcare needs of URM living in the Netherlands has not been conducted until now.

There are a few quantitative international studies that have addressed the mental well-being of this population (e.g., Derluyn, 2005, Felsman, Leong, Johnson, & Felsman, 1990, Masser, 1992; Sourander, 1998). From these studies and studies which have addressed both accompanied and unaccompanied minors, the conclusion can be drawn that URM experience high levels of emotional distress and are, per definition, a risk group for the development of psychological problems (Macksoud & Aber, 1996; Miller, 1996). From qualitative research that has been conducted among URM, it appears that the degree of psychological adaptation of refugee adolescents is negatively associated with having experienced many adverse life events (Halcon et al., 2004; Goodman, 2004; Rousseau, Said, Gagne, & Bibeau, 1998). Although there has been some progress made, there is still much work to be done among culturally diverse refugee adolescents in evaluating their well-being, fulfilling their emotional and mental healthcare needs, and charting the pathways that lead to resilience or vulnerability in their overall adjustment.

This dissertation addresses the assessment of psychological distress, mental healthcare needs and psychological adaptation of URM living in the Netherlands. This introduction will first depict how the methodological challenges that accompany conducting research with individual adolescents from many cultures were dealt with in this dissertation. In addition, the situation that the URM population was living in in the Netherlands during the years of the study, 2001-2004, will be briefly described as well as the design, objectives and research issues of this dissertation.

*Methodological challenges in conducting research among a culturally diverse population*

In countries that host refugee adolescents, there is often not one ethnic group or nationality represented, but many different countries and nationalities (UNHCR, 2004). This makes collecting scientific data for research among cultural and ethnic samples a very time-consuming process (Takeuchi et al., 1998). Obtaining a representative sample of refugee (or specific at-risk groups of) adolescents for research purposes has been repeatedly reported as being difficult due to factors such as the lack of trust/reluctance of the adolescents, lack of relevance for their (stress-filled) daily lives, and limited accurate information on the dimensions of the population (most studies are based on local or convenience samples) (Barenbaum, Ruchkin, & Schwab-Stone, 2004; Aptekar, 2004; U.S. Department of Health and Human Services, 2001). As there are often limited research funds, usually the most cost-effective means of attaining a target sample is used. This often results in researchers having to make a choice of assessing only specific populations (usually the largest) so that the results are unambiguous for one specific cultural group or they use convenience samples (Geltman et al., 2005). In this dissertation, it was possible to obtain a stratified large representative sample of the total population of URM living in the Netherlands through a known registration system, avoiding this common methodological limitation.

There are multiple methodological considerations surrounding the assessment of mental health of a population of heterogeneous refugee adolescents, particularly the way cultural factors may affect how an adolescent defines and seeks help for mental health problems. In the report of the Surgeon General on Mental Health: Culture, Race, and Ethnicity (2001) (p. 18) the methodological considerations that need to be evaluated in assessment in cross-cultural research can be broken down into at least three different types of equivalence; conceptual, scale, and norm. One of the methodological issues surrounding conceptual equivalence, is the question whether adolescents that come from different heritages think the same about concepts such as feeling sad, having arguments or experiencing nightmares? Scale equivalence evaluates if people from different cultural groups can similarly understand the standard formats and way items are presented on questionnaires. Finally, norm equivalence is important in being able to generalize what is normal or abnormal from one cultural group to another. The time-consuming process of the refinement of psychological assessment measures following these three overarching types of equivalence was carried out in this dissertation.

There are many other methodological issues which researchers are confronted with when conducting scientific research with culturally heterogeneous adolescent populations that can not all be addressed here. One can think of issues surrounding participation or attrition problems, collecting data from multiple culturally diverse informants, acculturation difficulties, amount of discrimination experienced by a certain ethnic group in comparison with other cultural groups, the number of adverse life events that a specific population has been exposed to etc., etc. However, no one single study, regardless of the quality and design, could possibly address all the known methodological issues that can be influenced by cultural factors. Furthermore, there is a substantial amount of information that has been collected indicating that cultural factors do not explain more variance in mental health than other known socio-demographic factors such as age, gender, socio-economic status, and living situation (European Commission, 2004; U.S. Department of Health and Human Services, 2001). Notwithstanding, it is essential when conducting cross-cultural studies (such as the present endeavor) an attempt is made to continually be aware of cultural factors and biases which might be hidden and to address them promptly and effectively in the design of the project. In doing so, the validity of the results can be enlarged. Consulting with multi-sectoral and multi-disciplinary experts and stakeholders who are involved with the study population at the macro, meso, and micro levels of society about the design of a cross-cultural study is essential to be able to not only detect cultural pitfalls and obstacles, but to find appropriate solutions to correct for cultural biases (Gielen, 2004). This culturally sensitive approach is the basis on which this dissertation has been assembled and how cultural similarities and differences were addressed throughout the study.

*Background situation of Unaccompanied Refugee Minors living in the Netherlands*

Taking care of foreign children and adolescents that were exposed to organized violence is not an unknown phenomenon in the Netherlands. After World War I (WWI), many Austrian and Hungarian children were temporarily cared for in the Netherlands (Sintemaartensdijk, 2002, p.11). Approximately 30,000 Dutch children after the Netherlands was liberated in WWII, were selected by Dutch general practitioners because they (1) had suffered more than other children, (2) were recovering from sickness, (3) were suffering from malnutrition and/or (4) had “nervous” symptoms (anxiety and sleeping problems) to be temporarily transported to other European countries to recover from the direct or indirect effects of war (Sintemaartensdijk, 2002, p. 33). In the 1980's, the Netherlands again opened its doors to a small population of unaccompanied refugee children from Vietnam and since then, have received and cared for thousands of URM.

Since the mid 1980's until 2001, the Netherlands had a liberal policy regarding granting asylum to URM. Almost all of the URM that entered the Netherlands were allowed to stay and integrate into Dutch society (see Appendix 1 for an overview of the number of new arrivals per year and total number of legal guardianships for URM living in the Netherlands for the years 1988 to 2005). Around 1995, the numbers of URM entering the Netherlands began to exponentially increase due to numerous armed conflicts and civil wars throughout the world (UNCHR, 2004). In the years preceding 2001, there was a dramatic increase in the number of URM living in the Netherlands, peaking at approximately 15,000 in 2001. Traffickers escorted around 60% of URM to the Netherlands (Olde Monnikhof & Tillaart, 2003), sometimes to be misused as prostitutes, as an “anchor” to make it possible to bring the rest of the family to the Netherlands, or for cheap labor to repay family debts in the country of origin. Seventy-three percent of URM in the Netherlands were not involved in making the decision to come to the Netherlands (Olde Monnikhof & Tillaart, 2003). Smit (1997) had found that one third of the URM population had been maltreated in their country of origin and that half had no father and a third no mother. Due to the large increase in numbers of URM in 2001, the immigration services for URM in the Netherlands, the legal guardian system (Nidos Foundation) and the residential facilities which housed URM, all became strained in trying to adequately handle the demand for their services.

A new restrictive governmental policy was implemented in 2001 with the main objectives being facilitation of repatriation to country of origin and restricting the number of URM that live in the Netherlands (Tweede Kamer-Dutch Parliament, 1999-2000). The starting point of the policy is not to allow the majority (80%) of URM to stay in the Netherlands longer than their 18<sup>th</sup> birthday (earlier if “adequate” care can be found in the country of origin) and that repatriation to the country of origin is imminent which has been decided before the asylum procedure even begins.

According to Cardol (2005), this policy is intrinsically flawed and infringes on the rights of the minor for development that has been established under Article 6 of the CRC. Specific aspects of the Dutch governmental policy in regard to URM such as estimation of biological age, interviewing techniques during the asylum procedure, right to legal representation, and the policy concerning reunion of family, all fall short of fulfilling the rights of unaccompanied minors (Cardol, 2005; p. 392-399). For example, if there is doubt surrounding the minor status, a subjective “optical” assessment is made by an (untrained) immigration service agent to estimate the approximate age of the minor. If there is further doubt surrounding this optical estimation, a biological assessment is conducted (i.e., x-ray of their collarbones and wrist bones) to verify/reject the asylum claim on the basis of minor status. However, these procedures cannot be considered absolutely conclusive (UNHRC, 2004). Furthermore, URM older than 12 years of age can be legally interviewed by immigration services without having their legal guardian or other legal representation present (Human Rights Watch, 2003), a blatant violation of their inherent rights. URM that are younger than 12 years of age are interviewed following a special protocol. However, this protocol has also been found not to fully respect the rights of URM (poor proficiency of interviewers, not enough time to prepare for the hearing, no legal representation during hearing) (Cardol, 2005, p. 272-279). Finally, URM which will not be allowed to live in the Netherlands and arrived after April, 2001 were placed in a “semi-locked” residential detention facility which restricted their freedom to move freely in the Netherlands and limited contact with Dutch society. The facility was known in the Netherlands under the name “The Campus”

and was not opened due to controversy until the 11<sup>th</sup> of November 2002 and was closed on January 1<sup>st</sup>, 2005 because it was found to not facilitate repatriation, be detrimental to the mental health of URM (Reijnveld, Boer, Bean, & Korfker, 2005), and 40% of the URM that were placed there ran away (Klaasen & de Prez, 2004). The agency of these young people was the main reason why this facility was closed.

Amidst this background of violation of rights, upheaval and changing policies, there were in 2001 many practical problems reported in referring unaccompanied minors to mental healthcare services by the Nidos Foundation (legal guardian organization of all of the URM living in the Netherlands). The problems that the guardians reported concerning mental healthcare services ranged from not being able to find services to professionals refusing to treat URM because the practical circumstances surrounding the lives of URM would inhibit any effect from therapy (Bean, 2002a). The Dutch mental healthcare professionals have also reported that URM are often not faithful to their therapy and often do not come or prematurely terminate treatment (Bean, 2002a).

Because of a lack of research on the mental health and mental healthcare utilization of URM (on a national and international level), an epidemiological, national and longitudinal research project “Unaccompanied Refugee Minors and Dutch Mental Healthcare Services” was started among URM living in the Netherlands and their guardians, teachers and professional mental healthcare providers in 2001. The goal of the project was to determine the severity of psychological distress of the URM population living in the Netherlands, their need for mental healthcare, and the availability of mental healthcare services for this population. The data collected during this project was used to write eight of the main chapters in this dissertation.

The infrastructure that exists in the Netherlands, one foundation - Nidos- which provides legal guardianship to all URM residing in the Netherlands, made it possible to draw a representative sample of the total population of URM between the ages of 11-17.5 years and to carry out such a large scale study among URM. In other countries, this infrastructure does not exist making it almost impossible to gather information on the mental health of URM on such a large scale and with the assistance from several informants. Finally, many organizations took part in this research project; 40 different regional offices of Nidos ( $\pm$  400 guardians), more than 150 schools ( $\pm$  470 teachers), and more than 20 different reception centers. Only through the flexible participation and active collaboration of so many organizations, could this project be successfully conducted.

### Objectives of this dissertation

The **first objective** of this dissertation is to expound on the possibility to validly and reliably use standard psychological questionnaires in assessing the psychological distress of a culturally heterogeneous sample of Unaccompanied Refugee Minors. The **second objective** is to determine the prevalence, severity and course of the psychological distress of URM living in the Netherlands. The **third objective** was to establish the needs, unmet need, and use of mental healthcare services among URM in the Netherlands. Finally, the **fourth objective** was to evaluate to what extent the severity of psychological distress of URM is associated with their psychological adaptation in the Netherlands.

### Design

The design of the main study was national, epidemiological, longitudinal, and used multiple informants. The study would consist of two assessment periods with an interval of twelve months in between. The written informed consent of the URM and their legal guardians was necessary for participation in the study. The project would take place throughout the Netherlands. Questionnaires (available in 19 bilingual [Dutch/ foreign] versions of the most prevalent languages of the URM in the Netherlands) would be administered to URM in groups (approximately 15 persons) at school or if necessary at reception centers. The mental health interviews would need to be conducted individually with URM. Master level (Dutch) students that had followed a short training would administer the questionnaires and mental health interviews. URM would need to be at least 11 years of age to be cognitively able to complete the questionnaires and not older than 17.5 years to be able

to locate them for the follow-up assessment. URM would need to have resided at least 4 months in the Netherlands to have some ability to communicate in Dutch. To be able to have an accurate representation of the total population of URM in the Netherlands, no attempt would be made to select URM for the study on any other socio-demographic factor. The legal guardians and teachers of URM would also receive questionnaires two times (interval of twelve months) by mail and return them by mail.

#### *Pilot study*

Great care was taken in designing the project. Prior to the start of the project, crisis intervention mental healthcare was arranged at mental healthcare facilities throughout the Netherlands for URM if they might experience psychological distress as a direct result of participation in this research project. Fortunately, it was not necessary to make use of the crisis care. Before the actual project started in May 2002, 183 URM and 10 guardians and teachers took part in a pilot study to (re-) test the research protocol and instruments (Bean, 2002b). The modifications to the lay-out and wording of the self-report questionnaires had been based on previous research (Bean, 2000). During the pilot study, 30% of the approximately 500 URM approached took part in the study. There was always a one week period between the introduction/explanation of the study and the assessment to allow URM sufficient time to consider taking part in the study. The pilot study was carried out with only URM who had been in the Netherlands for more than 4 months but less than one year. If there would have been severe language difficulties in filling in the questionnaires, it would have been with this group of URM. However, due to rapid transfers/re-location of URM it was very difficult to keep track of them. Most of the time, half or more of the URM that were present for the introduction of the pilot study, had moved before or on the assessment day. This situation was caused by the large numbers of URM that were still arriving in the Netherlands at that time (beginning of 2002). Five Master's level research assistants and the author conducted the assessments with small groups of URM (10-25). The assessments took place at two schools and 5 reception centers. One of the most important findings of the pilot study was that the size of the random sample that would need to be drawn for the main study would need to be 4 times as large as the final target sample size to be able to attain a large enough sample to validate the psychological instruments.

#### *The Main Study*

The original research proposal was to assess a sample of 1500 URM (minimum of 1000) for the first period and 500 URM for the second assessment period (follow-up) (Bean, 2002b). From the total population of approximately 12,000 URM under the age of 17.5 years (in 2002), approximately 4000 URM, ages ranging from 11 to 17.5 years were randomly selected from the Central Registrar of Nidos foundation. URM had to reside for at least 4 months in the Netherlands at the time of the selection to make sure that they could at least be able to communicate in very simple Dutch with the research assistants. Also, after 4-6 months in the Netherlands, the URM should have been placed from a temporary reception center into a more permanent residential setting, gotten used to their surroundings, should have been attending school, and have an guardian appointed to them. However, in actuality this was not always the case.

The research proposal was sent for approval to the Medical-Ethical commission of Leiden University Medical Centre. The research proposal was officially approved on the 6<sup>th</sup> of May 2002 and the main study started immediately hereafter. General public information about the study was sent to stakeholders, guardians, schools, and reception centers throughout the Netherlands to make sure that all the organizations and schools that would in some way take part in the study would be aware of the study, the reason for the study, the objectives of the study, and the contact person if they had questions or in the case of problems. After the general information was sent, specific information and permission waivers (Dutch and translated versions) were sent to the guardians to discuss with the URM. Both the minor and his/her guardian needed to give written permission before the URM would be allowed to participate in the study. They were also informed that participation was voluntary, the information that would be collected was confidential, and would in no way be used for or

against URM in their asylum procedure. The assessment period spanned an entire year, May 2002 tot May 2003.

After a period of 12 months had passed from the first letter, contact was again sought with the same URM that had participated in the first assessment period. Approximately every three months between May 2003 and May 2004, a sample of the URM that had taken part at the same time the year before was contacted to take part in the study again. In the second letter, the URM was informed over how many URM had taken place in the study, what the reason was for the second assessment, that the information that would be collected was confidential, that participation was voluntary and that this would be the last assessment.

### *Assessment procedures*

#### *URM*

In principle, the adolescents were to complete the questionnaires in small groups of 15 during school hours. The school is a neutral environment providing a secure structure for the administration of questionnaires. However, it was also necessary to administer the instruments in small groups of adolescents at reception centers or at the regional offices of the Nidos Foundation. These adolescents did not attend school or were absent on the day the questionnaires were completed. For each URM, at least three attempts were made to test URM that had given permission (and their guardian) to take part in the study (for T1 and T2). The URM, guardians, and contact person at the assessment location were all informed of the assessment appointment with the URM at least one week before it took place.

In total, 36 Master's level research assistants from 6 universities spread across the Netherlands, that were predominantly Dutch from ethnic origin worked on this project. At least three of the trained research assistants per 10 URM were present to conduct the short interview on mental healthcare needs and to provide an explanation regarding filling-in questionnaires in general and specific questions about items on the questionnaires. This explanation occurred every time before the instruments were filled-in and followed a standard protocol even if an URM was individually tested. This explanation took approximately 15 minutes. First, an introduction was made by the lead researcher and research assistants to clarify who they were and that they were part of a university and professional mental healthcare center and not working for the government. It was also very important during these 15 minutes to again explain the voluntary participation and the strict confidentiality of the study to try to reassure the URM that no information would be used against them. In addition, the random nature of how the sample was drawn was explained so that URM would not think they were personally singled out because something was wrong with them.

Administration of all the three self-report instruments and mental health questionnaire took approximately an hour to be completed during the first assessment. The mental healthcare questionnaire was always individually administered. During the second assessment period, it was sometimes necessary to re-administer all the instruments individually because a great proportion of the URM had been transferred (repeatedly) throughout the period between the assessments. This made it sometimes difficult to form groups because of the great physical distance between locations. The second administration lasted between 15 minutes up to an hour depending on the individual reading abilities of URM, including filling in the added Adaptation and Attitude questionnaire. Refreshments and a gift certificate for the cinema (worth 7.50 euro) were given to the URM during or after the administration of the instruments as a token of appreciation for their participation.

#### *Guardians and Teachers*

General information concerning the start of the project was distributed to all Nidos Foundation regional offices and schools which provide educational opportunities to URM. Forty-two regional offices of the Nidos Foundation were spread throughout the Netherlands in 2002. After permission slips were returned, two information packages (one for guardian and one for teacher) were sent to the supervisors of each regional office for each guardian that was responsible for one or more of the unaccompanied minors that had taken part in the study. The guardians received a letter with the questionnaires informing them about the study and giving instructions concerning how the questionnaires should be filled in. The guardians were instructed in the letter and by their supervisors that they could fill in the questionnaire or ask a staff member of the living unit/foster parent of the unaccompanied minors to do so. However,

the guardian remained responsible for retuning the completed questionnaires to their supervisors which in turn sent all the completed questionnaires from the regional office back to the research center. The guardians were reminded 3 times each assessment period to return the questionnaires. Unfortunately, because of their heavy caseload and/or the rapid turnover of personnel at that time many guardians did not return the questionnaires.

The guardian was also responsible to send the information package to the teacher. Enclosed in the information package for the teacher, was a letter describing the project, questionnaires and a stamped and addressed envelope in order to enable the teacher to return the completed questionnaires directly. The teachers received a letter with the questionnaires informing them about the study and giving instructions concerning how the questionnaires should be filled in. No list of teachers was supplied to the researcher, therefore making it impossible to remind the teacher to send the questionnaire back. Teachers could fill in the questionnaires anonymously.

The data that was collected during this research project is central in this dissertation and is used to make all “within” group comparisons. In chapters 2, 3, 4, and 6, other adolescents samples were also assessed to be able to make “between” population comparisons of psychological distress, maladaptive behaviors, stressful life events, and mental healthcare needs. In recent literature, within and between group comparisons have been called for to study differences in mental health and development (Fulgini, 2004). The characteristics of the other adolescent samples are described in the pertaining chapters.

### Structure of the dissertation

#### *Part 1: Assessment of psychological distress among a heterogeneous URM population*

The first section of this dissertation presents 5 chapters (2-6) that deal with the development and validation of psychological measures that assess the psychological distress and stressful life events of Unaccompanied Refugee Minors (URM). In this section the first objective of the dissertation, to expound on the possibility to validly and reliably use standard psychological questionnaires in assessing the psychological distress of a culturally heterogeneous sample of URM, is addressed. The first three chapters concern self-report instruments. The three self-report instruments (Hopkins Symptom Checklist - 37A [HSCL-37A], Stressful Life Events Questionnaire [SLE], and Reactions of Adolescents to Traumatic Stress Questionnaire [RATS]) were developed/adapted because at the start of this project there were no questionnaires available which measured internalizing distress, externalizing behavior, traumatic stress reactions and stressful life events, which were validated for refugee adolescents, which were translated in the necessary languages, which the item content did not refer to parents which might have been a painful confrontation for URM, and did not follow the five levels of cross-cultural equivalence suggested by Flaherty et al. (1988). Therefore, the endeavor was undertaken to compose a basic screening battery that would fulfill the above mentioned criteria.

The last two questionnaires which are validated for URM are the well-known Dutch version of the Child Behavioral Checklist and Teacher Report Form for respectively the legal guardians and teachers of URM living in the Netherlands. Using multiple informants in research among adolescents has become the norm primarily because of the important information that can be lost through self-reports and secondarily, because of the “objective” nature of the reporting of psychological distress from another point of view. Furthermore, it was imperative to examine to what extent the Dutch guardians and teachers were able to perceive the psychological problems that URM experience.

These five chapters serve as the scientific foundation on which the second section of the dissertation is built. The significance which can be attached to the results of any study is of course predetermined by the degree of reliability and validity of the psychological instruments that have been utilized. Earlier in this Introduction, the importance of the validation of psychological instruments among culturally heterogeneous population has been mentioned and is the main reason why half of this dissertation is devoted to the validation of assessment instruments.

*Part II: Severity of psychological distress, mental healthcare needs and psychological adaptation among URM in the Netherlands*

The second section of the dissertation focuses on the prevalence, severity and course of psychological distress among URM and their mental healthcare needs. In chapter 7, the URM population is compared with two other adolescent populations to assess to what extent the psychological distress of URM diverge from other adolescents and to compare different populations in an attempt to measure norm equivalence of the self-report instruments that were utilized. Chapter 8 is the heart of this section, covering the prevalence, course and agreement of reports of psychological distress given by URM, their legal guardians and teachers during both assessment periods. This chapter looks at the temporal course of the distress URM experience and if the significant adults in their lives are aware of the severity of the distress they experience. These two chapters (7 and 8) address the second objective of the dissertation. The following chapter concentrates on specific questions regarding the mental healthcare use, needs and unmet needs of URM, particularly in comparison with a Dutch normative sample. In this chapter the third objective is to attend to, i.e. establish what the needs, unmet needs, and use of mental healthcare services among URM in the Netherlands. Associations between the expression of traumatic stress reactions and the psychological adaptation of URM to their current situation is the focus of chapter 10 and the last objective of the dissertation. This chapter also investigates whether especially the comorbidity of internalizing and externalizing psychological problems with traumatic stress reactions impairs the adaptation of URM in the Netherlands.

At the end of chapter 10, a discussion follows in which the results of the study will be, above all, interpreted into implications for the mental healthcare field. The dissertation concludes with specific policy recommendations presented for clarity in the form of a stepped-care model. Because chapters 2 through 10 of this dissertation were written as individual articles, some overlap in the chapters was unavoidable, particularly regarding the method sections of each chapter.