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PREDICTORS OF PRETREATMENT DROPOUT IN A SAMPLE OF SYRIAN REFUGEE CHILDREN AND ADOLESCENTS WITH MENTAL HEALTH DIFFICULTIES IN LEBANON: A MIXED METHODS STUDY

by
ESTEFANIA KAMAL HANNA

A thesis
submitted in partial fulfillment of the requirements
for the degree of Master of Arts
to the Department of Psychology
of the Faculty of Arts and Sciences
at the American University of Beirut

Beirut, Lebanon
January 2022

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ACKNOWLEDGEMENTS

I would like to express my deepest appreciation to those who made this project possible. First, I would like to extend my warm and sincere gratitude to my thesis advisor and committee chair, Dr. Tania Bosqui, for her constant support, invaluable guidance, and patience in seeing this thesis come to completion. I would also like to thank Dr. Ghina Ismail, my committee member, for her constructive feedback and comments.

I also extend my sincere gratitude to the valuable research team from Queen Mary University of London. Dr. Fiona McEwen, Dr. Kristin Hadfield, Cassandra Popham, and Prof. Michael Pluess have all played crucial roles in supporting different parts of this thesis, providing continuous guidance and feedback.

I am also thankful for the team of research assistants - Sarah El Hechi, Yara Yazbeck, Joelle Jaber, Fatima Antar, Lynn Asseiran, Sabine Bou Saba, Grace Mouannes, and Hania Al Khattib. - who meticulously helped with the transcriptions and translations of the data, and for Jana Zbeeb for her support with quantitative data cleaning.

I also warmly thank all participating families for their participation in BIOPATH which is funded by the Eunice Shriver National Institute of Child Health & Human Development (NICHD; R01HD083387). The t-CETA study was funded by Elrha's Research for Health in Humanitarian Crises (R2HC) Programme, which aims to improve health outcomes by strengthening the evidence base for public health interventions in humanitarian crises; R2HC is funded by the UK Foreign, Commonwealth and Development Office (FCDO), Wellcome, and the UK National Institute for Health Research (NIHR) [https://www.elrha.org/]. Also, fieldwork was meticulously conducted by Médecins du Monde France (MdM) in Lebanon.

Finally, I am truly grateful to my friends who acted as a support system without whom this thesis would not have been completed, especially during the difficult times Lebanon was going through. Anas Mayya, Joelle Jaber, Nour El Ali, Julia Hammoud, Nicole El Hawi, Lana Tfaily, and Rajaa Barbary – I thank you and greatly appreciate your support.

ABSTRACT

OF THE THESIS OF

Estefania Kamal Hanna for Master of Arts
Major: Clinical Psychology

Title: Predictors of Pretreatment Dropout in a Sample of Syrian Refugee Children and Adolescents with Mental Health Difficulties in Lebanon: A Mixed Methods Study

Dropout from child and adolescent mental health interventions accounts for up to half of all patients who access them, is higher than adult dropout rate, and has serious implications for service delivery (Wergeland, Fjermestad, Marin, Haugland, Silverman, Öst, Havik & Heiervang, 2015). Research on predictors of pretreatment dropout has identified risk factors based on several variables. However, past research is limited by different operationalizations of dropout, poor differentiation among the different levels of dropout, and a lack of qualitative studies of reasons for dropout. In addition, no known study has explored pretreatment dropout in low resource humanitarian settings, where the context of delivery is often more complex and challenging.

This mixed-method study aimed to explore predictors of pretreatment dropout in a sample of Syrian refugee children and adolescents with mental health difficulties in Lebanon. Using secondary data ($N = 152$), we tested the effect of symptom profile, age, gender, socio-economic-status, distance to clinic, and time gap on attending the intake session.

Results indicated that only higher levels of PTSD were associated with higher likelihood of attendance. Families ($N = 9$) were also interviewed to explore qualitatively the reasons for dropout. Content analysis revealed 4 themes and 12 subthemes. Themes were around practical and logistical challenges, stigma and shame, perceptions of mental health services, and perceptions of mental health difficulties.

These findings inform future strategies to improve access to mental health care for this population, such as compensating for transportation costs and adopting community-based interventions.

Key words: pretreatment dropout, mental health, Syrian refugees, child and adolescent

TABLE OF CONTENTS

ILLUSTRATIONS

Figure

TABLES

Table

CHAPTER I

INTRODUCTION

A. Overview of Dropout

In psychotherapy, dropouts are patients who discontinue treatment prematurely. Rates of dropout are high across a wide range of psychological disorders and treatment modalities. This is alarming for a number of reasons. Patients who drop out from treatment may still have mental health difficulties that could benefit from intervention, and there is risk that patients' mental health may worsen. Missed sessions can also impact on limited human and financial resources (Barrett, Chua, Crits-Christoph, Gibbons, Casiano & Thompson, 2009), as well as on other patients in need who can be put on long waiting lists or denied access to treatment. Dropout also affects research as it leads to missing data and it reduces the statistical power of studies (Fernandez, Salem, Swift & Ramtahal, 2015). Finally, dropout inflates the results of studies on treatment efficacy when dropouts are excluded from the statistical analyses (Werbart & Wang, 2012).

This being said, dropout has received extensive attention in the literature throughout the years with one of the oldest meta-analyses dating back to 1975 (Swift & Greenberg, 2012). In fact, an abundant number of studies and meta-analyses have focused on treatment dropout including its different aspects: there are numerous studies on rates of dropout, factors leading to dropout, and on ways to prevent dropout. Despite the presence of a thorough literature, dropout rates are no different than they were more than 50 years ago (Barrett et al., 2009).

Although the current literature contributed greatly to our current knowledge on dropouts and its correlates, this literature still suffers from a number of limitations, which might explain the comparable past and present dropout rates.

B. Limitations of the Literature

The most important limitation present in the literature concerns the operationalization of dropout. Different studies have looked and operationalized dropout differently. For some studies, dropouts are participants who discontinued therapy before a specified number of sessions (for example, anyone who drops out before the third session) with the cut-off varying across and within studies (eg. Bados, Balaguer & Saldaña, 2007). For other studies, the number of sessions is irrelevant, and dropouts are anyone who stops attending treatment sessions without the therapist's approval. The same construct of dropout has also been operationalized by some researchers as skipping a specific number of sessions. Furthermore, dropout has been defined in some studies as a failure to complete a treatment protocol (Swift & Greenberg, 2012). Another operationalization of dropout is purely based on clinical judgment. Also, some studies define dropout in terms of clinical statistically significant change in the person's mental health. For example, in one study, statistical change was operationalized by administering standardized depression questionnaires to the patients before starting therapy and after discontinuing therapy; any person who has improved less than 33% was considered to be a dropout (Bados, Balaguer & Saldaña, 2007). Finally, a few studies have looked at dropout in terms of failure to show up to therapy sessions after an intake assessment or failure to show up for an intake assessment session after requesting an appointment (Reitzel, Stellrecht, Gordon, Lima, Wingate, Brown, Wolfe, Zenoz & Joiner, 2006).

While all of these operationalizations are based on good rationale, the diversity and inconsistency in the studies make it hard to compare the findings and to come up with reliable conclusions. In fact, varying definitions of dropout represent contradictory constructs and lead to different results, both in terms of the rate of dropout and in terms of its predictors (Barrett et al., 2009).

This relates to another limitation in the current literature, which is that participants drop out at different stages in the process of therapy, with most of them dropping out early on rather than later (Fernandez, Salem, Swift & Ramtahal, 2015). In other words, there are people who drop out before even attending the first session of therapy, called ‘pretreatment dropouts’ or ‘non-attenders’. There are people who drop out in the introductory stages of therapy in which rapport and central features are being implemented, called ‘early dropouts’. Then, there are people who drop out later on in therapy when the sessions become more individualized and core features of treatment are being implemented, called ‘late dropouts’. Finally, there are people who do not dropout and who end up attending the whole therapy process, called ‘completers’. Interestingly, a few meta-analyses have shown that every stage at which dropout occurs has its own predictors and challenges (Fernandez, Salem, Swift & Ramtahal, 2015; Swift & Greenberg, 2012). In other terms, studies that explore dropout as a unilateral construct, end up mixing up different unrelated predictors which leads to unprecise and misleading conclusions.

Keeping these limitations in mind, it is not surprising that the current literature on dropout is extensive but not informative. In fact, different meta-analyses have inconsistent results about the same predictors (Imel, Laska, Jakupcak & Simpson, 2013). For example, while many studies and some meta-analyses show that symptom severity, therapists' experience, lower socio-economic status, and being from a minority group are all associated with higher prevalence of dropout from treatment, other studies and meta-analyses showed no effect of these same variables. For example, a meta-analysis conducted in 2012 shows that the therapist's level of experience is a significant predictor of dropout, specifically, participants are more likely to drop out when the therapist is a trainee as compared to when they have a degree and they are experienced (Swift & Greenberg, 2012). Another meta-analysis looked at the same variable of therapists' experience and the results showed that the difference in dropout with trainee therapists and with experienced therapists is not significant (Fernandez et al., 2015).

C. Literature on Barriers to Seeking Treatment

While the literature on dropout suffers from important limitations, the thorough literature on barriers to seeking mental health treatment is important as there are some similarities between the two. Dropping out from treatment - in which the person gets involved in treatment then stops - and barriers that prevent the person from seeking treatment in the first place are two different constructs. However, there is a notable overlap in the studies looking at these two constructs, in terms of literature, methodology, and results. Hence, a quick overview of the literature on barriers to seeking treatments is informative.

A recent study involving 121,899 participants from 24 countries including Lebanon have looked at barriers to initiating mental health treatment (Andrade, et al., 2014). In specific, this study looked at both attitudinal barriers (including wanting to handle the problem by their own, perceived ineffectiveness of treatment, believing that the problem would get better, stigma, etc.) and structural barriers (including problems related to finances, transportation to the clinic, availability of a mental health professional, etc.).

Among the different results, this cross-national study showed that attitudinal barriers were more important than structural barriers. In fact, the most common barrier to seeking treatment is low perceived need, and this was still true in moderate and severe cases of mental disorders. It was hypothesized that this is related to mental health literacy, including stigma, knowledge and understanding of mental health, and cultural and social factors. Among those who had a perceived need for treatment, a desire to deal with the problem by themselves was the most common barrier to treatment. Again, this is hypothesized to be linked to stigma and fear of discrimination and negative consequences. Finally, in lower- and middle- income countries (such as Lebanon) structural barriers were commonly reported. These include problems getting to the clinic and absence of trained mental health professionals.

Similar results have been replicated in other studies and systematic reviews. Most recently, a systematic review included 44 studies to look at barriers and facilitators of seeking mental health treatment in children and adolescents (Reardon, Harvey, Baranowska, O’Brien, Smith & Creswell, 2017). Four themes were particularly related to parental perceived barriers for seeking treatment. First, systematic/structural issues which include the cost of treatment, problems getting to the clinic (for example, clinic is far, or problems with transportation), and long waiting lists and lack of available mental health professionals. Second, views and attitudes towards services and treatment which include issues related to confidentiality, trusting the therapist, the quality of the service, language and culture, other people's views and perceptions including stigma, wanting to solve the problem by their own, and so on. Third, knowledge and understanding of mental health problems and treatment which include parent recognition of the problem and its impact and severity, parent perception of need for treatment, child recognition of the problem and perception of need, and parent and child understanding of help seeking. Finally, family circumstances include the support of the family, other responsibilities and commitments in the family, and the time commitment needed for treatment. This thorough review of barriers to seeking treatment overlaps with many of the findings on dropout.

D. Current Literature on Pretreatment Dropout

Going back to dropout, and to move forward in the research of pretreatment dropout it is not enough to be aware of the limitations of the current literature, but it is also necessary to acknowledge what this literature offers in terms of what we know, what is inconsistent, and what is missing.

To start with, while it can be argued that we can look at pretreatment dropouts - or non-attenders – in a positive light as their nonattendance can be an indicator of their problems becoming better or of them finding an adequate outside source of support, it is generally seen as a negative outcome. This has been tested in a study in which outpatients who failed to show up for therapy sessions after the intake assessment were contacted again, and only 29% of them have reported that their previous chief complaint has been ameliorated or resolved (Reitzel et al., 2006).

Adding to that, as described above, dropout can be seen at different stages of the therapeutic process and dropout at each stage has its own predictors and challenges.

Interestingly, the group of pretreatment dropouts in and of itself is a heterogeneous group. Pretreatment dropouts encompass people who actively refuse to start therapy as well as people who fail to schedule an appointment or to show up for an appointment (Issakidis & Andrews, 2004). In some studies, these are considered as separate groups and not combined, and in others, these are combined, as failing to show up for the first therapy session can be seen as a passive form of treatment refusal. And yet, in other studies, these two groups are combined with other stages of dropout which further complicates the results and the conclusion that can be drawn. Consequently, results are inconsistent even in studies focusing on pretreatment dropout.

In fact, a large number of different variables have already been studied quantitatively in relation to pretreatment dropout. As an attempt to make sense of the numerous variables and to present a summarized framework to the factors predicting non-attendance, different studies have come up with different models, similar in parts, and complementing each other in other parts.

One model suggested by Reitzel et al. (2006), looks at three sets of characteristics in relation to patients' nonattendance; patients' characteristics, therapists' characteristics, and administrative characteristics. Variables related to the patients include gender, symptomatology or primary diagnosis, level of education, degree of social isolation, socioeconomic status, and sociodemographic characteristics such as the presence of other children at home, and minority group membership. Variables related to the therapist include level of experience, level of ethnocentricity, expectations of improvement, and liking/disliking the patient. Administrative variables include interruption of the therapeutic relationship and the time gap before a scheduled appointment.

In another model, predictors of pretreatment dropout were classified and understood in terms of clinical characteristics (mainly the primary diagnosis), sociodemographic characteristics (such as the presence of other children at home), system characteristics (such as individual vs. group treatment), and interaction effects (Issakidis & Andrews, 2004).

A third model explores pretreatment dropout through four broad categories; patient characteristics, enabling factors (including socio-economic level), need factors (these are related to the diagnosis, the prognosis, and comorbidities), and environmental factors (Barrett et al., 2009).

1. Age and Gender

As age and gender are key demographic variables, they have been explored in all studies looking at dropout. Results concerning both variables are inconsistent. Concerning age, older studies show no significant difference in age between those who don't start treatment and those who do (Werbart & Wang, 2012). Interestingly, a meta-analysis including 115 studies and combining children, adolescents and adults showed that although children and adolescents are slightly more likely to not start treatment as compared to adults, this difference is not significant (Fernandez, Salem, Swift & Ramtahal, 2015). Similarly, some studies show no significant gender difference between treatment non-starters and treatment starters (Killaspy, Banerjee, King & Lloyd, 2000). On the other hand, the literature also contains some studies showing that younger patients are more likely to fail to start treatment as compared to older ones (Baruch, Vrouva & Fearon, 2009), and other studies showing that being older is a significant predictor of pretreatment dropout (Werbart & Wang, 2012). Again, gender has similar inconsistent results in the literature with some studies presenting evidence that males are more likely to drop out pretreatment as compared to females (Werbart & Wang, 2012), and other studies showing that being female is a significant predictor of not starting treatment as compared to being a male.

2. Symptom Profile and Symptom Severity

Symptom profile or diagnosis is one of the variables commonly studied in relation to pretreatment dropout, with inconsistent results overall. Some studies in the literature show that the primary diagnosis is a significant predictor of pretreatment dropout (Issakidis & Andrews, 2004). In fact, in one meta-analysis consisted of 115 empirical studies on pretreatment dropout and included children, adolescents, and adults, participants with depression were at the highest risk of not starting treatment followed by participants with eating disorders (Fernandez, Salem, Swift & Ramtahal, 2015). In a study conducted in Sweden on dropouts, symptomatology and diagnoses were also analyzed. It was shown that patients with axis I disorders, patients with psychotic features, and patients with a high risk of being dangerous to themselves or to others are the ones who are at the highest risk of not starting treatment (Werbart & Wang, 2012). This indicates that more vulnerable patients are most at risk of pretreatment dropout. Same studies in the literature have explored the role of severity and functional impairment on the risk of pretreatment dropout and have showed that the more severe the symptoms are, the more at risk of dropout the patient is (Issakidis & Andrews, 2004). No known studies have been conducted on impairment directly, rather than symptom severity.

3. Socio-Economic Status

Having lower socio-economic status (SES) and being part of an ethic minority group are the only consistent predictors of children and adolescents' dropout in general and pretreatment dropout specifically (Swift & Greenberg, 2012; Barrett et al., 2009; Topham & Wampler, 2007). Almost all meta-analyses and studies in the literature present evidence for SES as being a significant predictor of starting therapy (Werbart & Wang, 2012). This finding is of high concern especially with community mental health centers. In such cases, the aim is to provide mental health support to the people who are marginalized or less advantages financially, but in fact, these are the people that are more likely to fail to show up for treatment (Barrett et al., 2009). Adding to that, studies have also consistently shown that having at least one child other than the identified patient is a significant predictor of not starting treatment (Issakidis & Andrews, 2004).

4. Time Gap and Distance to the Clinic

The distance that participants have to travel to get to the clinic has also been explored in a few studies (Issakidis & Andrews, 2004). In one study, this variable has been investigated in a sample of adult psychiatry outpatients. Patients' proximity to the clinic was determined from the postal code if the residence then concerted to numerical values for analysis. The results show that distance to the clinic significantly predicted non-attendance; those who are more distant were more likely to dropout (Campbell, Staley & Matas, 1991).

Another important variable that has been studied in relation to pretreatment dropout is the gap period between the intake assessment and the therapy session appointment. In a study with adult patients presenting with a variety of diagnostic profiles (such as mood disorders, anxiety disorders, substance-related disorders, personality disorders, psychotic disorders, and adjustment disorders), the time gap was operationalized and measured in terms of the number of days that had passed between the screening appointment and the assignment to a therapist (Reitzel et al., 2006). With pretreatment dropout being the dependent variable, results showed that the longer patients had to wait, the more likely they were to drop out and fail to show up once an appointment was given. More specifically, waiting 15 days or more was positively correlated with patients' non-attendance. As the researchers hypothesized, merely giving patients an appointment might increase their self-efficacy and provide them with a sense of relief that they will receive the treatment they need (Reitzel et al., 2006).

While the importance of time gap has been reported in multiple studies (Barrett et al., 2009), a relatively older study shows contradictory results. In a prospective cohort study with adult attenders and non-attenders in an outpatient psychiatric sample were compared in terms of the number of days they had to wait before getting a therapy appointment, and they found that there was no significant difference in dropout (Killaspy, Banerjee, King & Lloyd, 2000).

Consequently, for the time gap, no clear conclusion can be drawn from the literature.

E. Qualitative Literature on Pretreatment Dropout

Given the inconsistent results with most quantitative variables, studies have started including qualitative methods to better explore and analyze in-depth dropout and its predictors (Wilson & Sperlinger, 2004).

To our knowledge, studies with qualitative methods in the literature all explore early and late treatment dropout with no study exploring pretreatment dropout qualitatively.

For example, in two parallel studies conducted in 1994 and 1996, patients who have discontinued treatment and their therapists were interviewed separately and the results show the differences in their perceptions of the reasons that led to dropout (Wilson & Sperlinger, 2004), which in a 1990's UK context includes different therapists/patients' perceptions and expectations of treatment, and different needs and goals. A more recent study was conducted to explore the predictors of early dropout. Areas tackled in the patients' interview included perceptions of the therapist, expectations of treatment, experience of the therapeutic approach, and factors external to the therapy. In all of these studies, the interview questions were chosen based on what the dropout literature presents in terms of predictors as well as on clinical experience. These studies have been able to shed light on the reasons why dropout occurs, rather than just the characteristics of those who dropout. Caution should be taken however, in setting up qualitative interviews, to prevent the tendency of participants to give positive feedback and to report satisfaction with treatment even when they have negative reasons that led to the discontinuation (Barrett et al., 2009).

F. Pretreatment dropout in Lebanon and in Humanitarian Settings

To our knowledge, no study in Lebanon has explored any type of dropout of treatment. However, barriers to seeking treatment and services in Lebanon were explored in a study in 2018 using a mixed method approach (Karam et al., 2018). Among the various results, the study found that people with higher income and higher levels of education are more likely to seek treatment as compared to those with lower income and lower levels of education (Karam et al., 2018). This is in line with the wider literature on dropout.

Adding to that, and to our knowledge, no study has explored pretreatment dropout in a humanitarian setting. Understanding the predictors of pretreatment dropout for services that are already limited in humanitarian settings is vital, because these populations are likely to be disproportionately affected by the socio-economic characteristics that are associated with dropout and are also likely to have a much greater need for mental health and psychosocial support (Charlson et al., 2019; Bronstein & Montgomery, 2011).

G. Research gap and importance of this study

The current study aimed to overcome some of the limitations and gaps in the existing literature. As already mentioned, most studies in the literature are quantitative and the few existing qualitative studies explore early and late dropout. Also, most of the literature on dropout includes adult participants and there is a lack of studies looking at pretreatment dropout in children and adolescents only. Finally, there is also a lack of pretreatment dropout studies in the Arab world, especially in a humanitarian setting.

To address these limitations, using quantitative as well as qualitative measures, this study aimed to explore the predictors of pretreatment dropout in a sample of Syrian children and adolescents living in informal tented settlements (ITSs) in Lebanon.

CHAPTER II

AIMS AND HYPOTHESES

This study aimed to identify the key reasons for declining to engage in an offered evidence-based mental health intervention for Syrian refugee children and adolescents resident in Lebanon who have mental health difficulties and have expressed a need and interest in treatment. This is the first study, to our knowledge, that explored pretreatment dropout in a humanitarian setting using a mixed methods approach.

A. Quantitative Component

Null Hypothesis: There will be no difference between participants who dropped out pretreatment and those who started treatment.

While some studies found evidence for younger people being more likely to drop out pretreatment, other studies found contradicting results.

Hypothesis 1: Pretreatment dropouts will differ significantly from those who started treatment in terms of age.

Gender has also yielded inconsistent results in relation with non-attendance.

Hypothesis 2: Pretreatment dropouts will differ significantly from those who started treatment in terms of gender.

Different studies have found evidence for different symptom profiles as being more likely to dropout pretreatment. Also, studies in the literature show that patients with more severe symptoms are more likely to dropout as compared to patients with less severe symptoms.

Hypothesis 3: Pretreatment dropouts will differ significantly in terms of symptom profile as compared to those who started treatment.

Hypothesis 4: Higher symptom severity and impairment will significantly predict pretreatment dropout.

Consistently, the literature shows that participants with lower socioeconomic statuses are more likely to dropout pretreatment as compared to others with higher socio-economic statuses.

Hypothesis 5: As compared to those who started treatment, those who dropped out pretreatment are more likely to be from lower socio-economic groups.

The literature presents inconsistent results in the relationship between time gap and pretreatment dropout.

Hypothesis 6: Pretreatment dropouts will differ significantly in terms of time gap as compared to those who started treatment.

A few studies in the literature show evidence that patients who live further from the clinic are more likely to dropout as compared to those who are less far.

Hypothesis 7: Longer distances needed to reach the clinic will significantly predict pretreatment dropout.

B. Qualitative component

The qualitative component of the study was designed to explore with children and parents variables related to dropout based on the existing literature and on the team's clinical experience of working with this population. Some of these variables and factors included parents and children's perceptions of mental health (including understanding of mental health, stigma towards mental health and misconceptions, and ways of coping). Other questions tackled factors such as their expectations of treatment, their experience as a minority group (feeling discriminated against, not being understood), their pretreatment alliance with the counselor over the phone, and concerns of confidentiality. Also, and in line with the current literature, the interview tackled structural factors (perception of the team as reliable, structured, and professional or not) and practical problems (having other children, finding the clinic far, not having the money up front for transport).

CHAPTER III

METHOD

A. Research Design

This study employed a mixed methods approach. For the quantitative part, the predictors are age, gender, symptom profile (operationalized through four variables; depression, anxiety, PTSD, and externalizing problems), functional impairment, socio-economic status (SES) (operationalized through three variables, cash assistance, job classification, and literacy level), time gap between the phone assessment and the intake session, and distance needed to get to the clinic. The outcome variable is pretreatment dropout. Data was derived from an existing study using secondary analysis. For the qualitative part, semi-structured interviews with parents and children explored views of mental health and mental health services, reasons for asking for treatment, reasons for dropout, as well as suggestions for service access improvement.

B. Power Calculation

Given that the quantitative part of the study is based on secondary data that has already been collected, we used the existing sample size and estimated effect size to calculate the study’s statistical power, using the software G*Power 3.1 (Faul, Erdfelder, Buchner & Lang, 2009). The effect size estimation was inputted as OR=1.8, based on previous studies on dropout using a comparable methodology (Werbart, & Wang, 2012; Issakidis & Andrews, 2004). With alpha set at 0.05, for a total sample size of 152, the study is able to achieve power of 0.80. This indicates that the sample size is large enough to conduct a logistic regression.

For the qualitative part of the study, we aimed to complete interviews with a minimum of 6 families (one target child and at least one parent) and up to 10 families. This is in line with other studies on dropout in the literature.

C. Participants

Participants were 8 to 17 years old Syrian children and adolescents, and their parent(s), living in Lebanon, who were experiencing clinically significant mental health difficulties, have been part of the BIOPATH study, and have showed interest in receiving mental health treatment when it was offered to them through the NGO who acted as research partners, Médecins du Monde (MdM), during recruitment for the t-CETA study.

BIOPATH (Biological Pathways of Risk and Resilience in Syrian Refugee Children) is a longitudinal study of 1,600 Syrian families in Lebanon (see McEwen et al., 2021a). This study explored children's responses to war and displacement, and the reasons that explain why children have different reactions. Children in BIOPATH who identified as having mental health difficulties requiring treatment were offered free mental health treatment through Médecins du Monde, in part through the t-CETA (Development, Piloting and Evaluation of a Phone-Delivered Psychological Intervention) Randomized Control Trial (see Pluess et al., 2019). Participants who took part in the t-CETA study received CETA (Common Elements Treatment Approach) delivered by telephone or treatment as usual face to face, but all had to attend the first session in person. The aim of the clinical trial was to explore whether CETA delivered through the phone and by trained lay providers is as effective as standard mental health treatment delivered face to face.

For the qualitative interviews, and in line with common standards for qualitative methodology (Sandelowski, 1995), we have purposefully selected families (caregivers and children/adolescents) based on the below criteria.

1. Inclusion Criteria

a. For the quantitative component

All children and adolescents who took part in year 2 of the BIOPATH study, reported mental health difficulties, and who expressed an interest in treatment, were included in the analysis.

Mental health difficulties were operationalized as scoring above cut-off on at least one of the following mental health screening tools: Center for Epidemiological Studies Depression Scale for Children (CES-DC; which screens for depression), Screen for Child Anxiety Related Emotional Disorders (SCARED; which screens for anxiety disorders), Child PTSD Symptom Scale (CPSS; which screens for PTSD), Strengths and Difficulties Questionnaire (SDQ; which screens for internalizing and externalizing behavior problems).

b. For the qualitative component

1. Families who expressed an interest in treatment initially but who dropped out before attending any session.
2. Priority in the selection of families was for families whose children have impairing mental health problems. This was operationalized through two methods:

a. Children scoring above cut-off on at least one of the mental health screening tools mentioned above (CES-DC, SCARED, CPSS, SDQ).
b. Children showing functional impairment as measured by WHODAS (a disability/ functional impairment questionnaire).

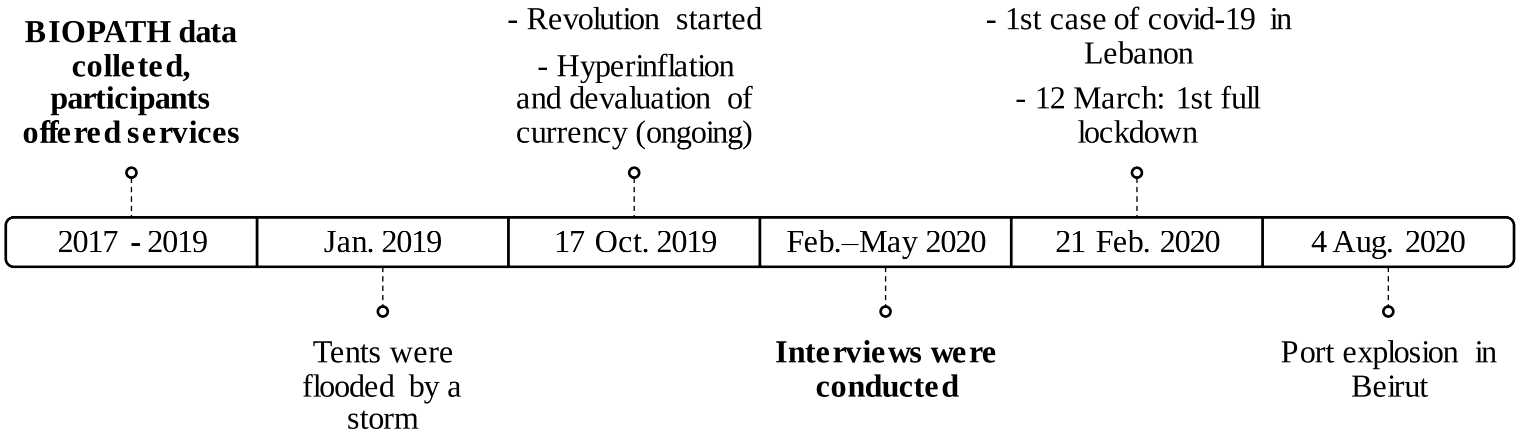
2. Exclusion Criteria

<u>a. For the qualitative component</u>

1. Families in which children/adolescents' mental health has deteriorated to the point that it was unclear if they have capacity to assent were not included (and appropriate referral sought). This was operationalized based on clinical judgment and parental consent.
2. Families in which the main caregiver – the person who was involved in the BIOPATH study and who showed interest but then declined participating in treatment - was no longer present were excluded. This is because it would be unhelpful to ask questions about the reasons for asking for treatment and the reasons for denying treatment for a caregiver who was not involved in asking for treatment and declining treatment.
3. Children/adolescents who were not aware that they were offered treatment that the caregiver declined were excluded (for example, families in which the caregiver alone showed interest in treatment without the knowledge of the young person). This is first to avoid disclosing confidential information to the child/adolescent, and second, because it would not be helpful to ask the young person about reasons for asking for treatment and reasons for declining treatment.

D. Setting and Context

Figure 1. Contextual Background



An overview of the context around which the study took place is warranted (see figure 1). In fact, Lebanon witnessed a succession of unprecedented major events in the last few years. BIOPATH data for year 1 was collected between October 2017 and January 2018, and for year 2 between September 2018 and January 2019. In January 2019, refugee's informal tented settlements were flooded by a storm, majorly affecting tents, furniture, and personal belongings. The flooding led to the death of one person, affected more than 11,000 individuals, and forced hundreds of refugees to abandon their homes (Champagne & Hariri, 2019). Later in October 2019, and due to the serious political and economic instability, people took to the streets protesting in all areas of Lebanon, blocking roads across the country.

Frequent road closures lasted for months after the start of the revolution. In fact, between February and May 2020, the interviews for this study were conducted over the phone and Lebanon was still facing daily instability, occasional violence in the streets, and road closures. Closely following the revolution, Lebanon faced its most severe economic collapse with a major hyperinflation and devaluation of the currency. In fact, the Lebanese currency lost more that 90 percent of its value in the last 2 years (Malik & Haidar, 2021). With this collapse, around three-fourths of the population currently lives under the poverty line, critically exacerbating the challenges of refugees and families who had already low socio-economic statuses. This crisis affected almost all areas of daily life such as leading to electricity and fuel shortages, and to medicine shortages. In addition, the start of the interviews overlapped with the beginning of the coronavirus pandemic in Lebanon, with the first case of the virus being detected in February. This was followed by the first lockdown in March 2020. The under-resourced health system and the inability to appropriately respond to the outbreak was once again added to the pre-existing challenges in the country, leading to even more instability. Specific to the refugee population, the crowded living conditions with inadequate sanitation and limited access to health care were combined with the high levels of stigma endorsed by the host country further exacerbating the population's vulnerability (Fouad, McCall, Ayoub, Abu-Raddad & Mumtaz, 2021). On August 4 of 2020, the unparalleled Beirut port explosion took place, leaving the capital in ruin, killing more than 217 people, injuring around 7,000 individuals, and displacing 300,000 person (Amnesty International, 2021). This blast was described as one of the strongest non-nuclear explosions to ever happen.

E. Measures

1. For the quantitative component

All scales and measures described below for the quantitative component were administered to participants through the BIOPATH study (see McEwen et al., 2021a).

a. Demographic characteristics

Background information from the children/adolescents included: age, gender, and nationality.

Background information from the caregiver(s) included: gender, relationship to the child, nationality, where they live now, and how many children they have.

In order to operationalize socio-economic status, 3 different areas were assessed.

First, to check for literacy level, caregivers were asked "Can you and/or other adults in your household read and write? For example, read newspapers and write a letter [Answer about the person with the highest literacy in the household]". This was rated as "Not at all", "A little", "More or less", "Mostly", or "Absolutely yes".

Caregivers were also asked whether they had a job in Syria, before the war. Options to this item included working as 'a manager or a professional', 'a supervisor, a clerical, a skilled manual worker, or a service or sale worker', 'a semi-unskilled worker', and having 'never worked or been unemployed for a long period of time'. This question had poor distribution as 3 caregivers (2%) reported previously being a manager or a professional; 48 (31.6%) reported previously working as a supervisor, a clerical, a skilled manual worker, or a service or sale worker; 76 (50%) reported previously working as a semi-unskilled worker; and 17 (11.2%) reported never working or having been unemployed for a long period of time. To increase variability, the first two categories (manager and supervisor) were merged together for analysis.

In addition, caregivers were asked whether they were receiving any food or cash assistance. For both items, participants were asked to report the sum value received in the last month. The options included '$0-15 / LBP 0-23,000', '$16-30 / LBP 24,000-46,000', '$31-50 / LBP 47,000-76,000', $51-100 / LBP 77,000-151,000', $101-150 / LBP 152,000-227,000' and '>$151 / >LBP 228,000'. The majority of the sample (*n* = 115, 75.7%) reported receiving higher than 151$ of food assistance in the last month and 26 participants (17.1%) reported not receiving any food assistance. Cash assistance on the other hand was divided as around half of the sample (*n* = 78, 51.3%) receiving higher than 151$ in the last month, and 69 participants (45.4%) not receiving any cash assistance. Due to poor distribution on the different categories of these two variables, food assistance was excluded from our analyses and cash assistance was included with only two categories (receives assistance, *n* = 83 vs. does not receive assistance *n* = 69).

Demographic characteristics administered can be found in appendices A and B.

<u>b. The Center for Epidemiological Studies Depression Scale for Children (CES-DC)</u>

The CES-DC is a 20-item self-report measure that was developed to assess for the severity of depressive symptoms. The items in this scale are rated during the last month using a 3-point Likert scale ranging from 0 (not at all) to 3 (a lot). Scores are added up to give an overall score ranging between 0 and 60, with higher scores indicating higher severity of depressive symptoms. A cutoff score of 15 is used to suggest depressive symptoms in children and adolescents. However, in Arabic speaking populations, there is evidence showing that a cut-off of 15 leads to a higher prevalence of depression than expected, so a higher cut-off is needed (ex. cut-off point of 21) (Salah, Yamamah, Megahed, Salem, El-din & Khalifa, 2013). Examples of items include “I felt like I couldn’t pay attention to what I was doing (e.g., homework, playing, watching TV, doing chores) and “I felt lonely, like I didn’t have any friends”. Factor analysis conducted as part of the BIOPATH study (see McEwen et al., 2021a) shows that the CES-DC scale has 3 main factors: behavioral, cognitive, and a happiness factor.

In the BIOPATH study, a reduced version of 10-items of the CES-DC was administered to children and adolescents to assess for depression. The items in the reduced version were carefully chosen to match the understanding of our population after conducting factor analysis, integrating qualitative feedback, and pilot testing with Syrian children in Lebanon.

The CES-DC has good psychometric properties in general (Faulstich, Carey, Ruggiero, Enyart & Gresham, 1986). It has a test-retest reliability of .51 ($p < .005$) and a coefficient of internal consistency of .84. It also has a moderate concurrent validity. More specifically, the translated Arabic version of the CES-DC showed reasonable psychometric properties when used with a sample of young Arab women (Ghubash, Daradkeh, Al Naseri, Al Bloushi & Al Daheri, 2000). In this sample, the measure showed good reliability (alpha=.88, average re-test reliability ICC=.59) as well as good validity, discriminating between participants with depression and participants without depression (cut-off point of 21: AUC=.84, sensitivity=.82, specificity=.83).

The reduced version of the CES-DC can be found in appendix C.

c. The Screen for Child Anxiety Related Emotional Disorders (SCARED-C) Scale

The SCARED scale is a self-report measure that was developed to screen for anxiety disorders in children and adolescents ages 9 to 18. Specifically, it screens for general anxiety disorder (GAD), separation anxiety disorder (SAD), panic disorder (PD), social phobia, and school phobia. There are two versions of SCARED, a child version (SCARED-C) and a parent version (SCARED-P). This scale has 41 items that ask participants about the severity of symptoms for the past month. Severity is rated on a 3-point Likert scale ranging from 0 (not true or hardly ever true) to 2 (very true or often true). Example of items include "When I get frightened, I feel like I am choking" and "I worry about things working out for me". A cutoff score of 25 (or above) indicates the presence of an anxiety disorder.

The SCARED scale has good psychometric properties (Birmaher, Khetarpal, Cully, Balach, Kaufman & Neer, 1997). The overall score has a coefficient alpha of .93. It also has good test-retest-reliability for its overall score, with a coefficient alpha of .86. The test-retest reliability for individual factors (for the different types of anxiety assessed) ranges between .70 and .90. This scale has also showed good discriminant validity, both between children with anxiety versus children without anxiety and among the different disorders of anxiety.

In addition to that, the SCARED scale had been translated to Arabic. This Arabic version has been tested with a sample of child and adolescent psychiatric outpatients in Lebanon and yielded satisfactory psychometric properties (Hariz, Bawab, Atwi, Tavitian, Zeinoun, Khani, Birmaher, Nahaz & Maalouf, 2013). SCARED-C has great internal consistency with a Cronbach's alpha of .91. Cronbach's alpha for the 5 specific anxiety disorders ranges between 0.65 and 0.85. SCARED-C also has satisfactory discriminant validity and convergent validity.

In the BIOPATH study, a shortened version of the SCARED-C was administered to children and adolescents. This version had only 15 items, as there was higher interest is assessing the presence or absence of an anxiety disorder in general, rather than a specific anxiety disorder. The items included in the shortened version were chosen as a result of factor analysis, qualitative feedback and pilot testing with Syrian refugee children in Lebanon. More specifically, items related to school anxiety were removed, as this does not apply to an important percentage of our population.

The shortened version of the SCARED-C can be found in appendix D.

d. Child PTSD Symptom Scale (CPSS)

The Child PTSD Symptom Scale (CPSS) is a self-report measure designed to assess PTSD diagnosis and symptom severity in children and adolescents ages 8 to 18 (Foa, Johnson, Feeny & Treadwell, 2001). It has 17 items that map onto the symptoms required for a PTSD diagnosis in the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV). The questions in this scale assess for the frequency of each symptom of PTSD in the last month. Examples of items include “trying not to think about, talk about, or have feelings about the event” and “not feeling close to people around you”. Participants rate the frequency of each item on a 4-point Likert scale ranging from 0 (not at all or only at one time) to 3 (5 or more times a week / almost always). The answers to the 17 items are added up to give a total score ranging from 0 to 51, with higher scores indicating higher symptom severity. Originally, a cut-off score of 11 indicated the presence of PTSD (Foa, Johnson, Feeny & Treadwell, 2001).

However, based on clinical experience, a cut-off score of 15 appears to be more appropriate to determine PTSD. Adding to that, the CPSS also gives three individual scores for the three clusters of PTSD symptoms in the DSM-IV (reexperiencing, avoidance, and arousal). It also has 7 items that assess daily functioning during the past 2 weeks.

In the BIOPATH study, the 17-items CPSS was administered to children but the scale on daily functioning was not used as it overlaps with the Strengths and Difficulties Questionnaire (SDQ) which was also administered. In addition to the 17 items, an 18th item about sleep was added to create a 3-item subscale about sleep disturbances. Also, the instructions and the wording of one specific item were slightly modified to better fit the population and their setting.

The CPSS has been shown to have good psychometric properties (Foa, Johnson, Feeny & Treadwell, 2001). It has high internal consistency for the overall symptom severity score (coefficient alpha .89), as well as for the severity score of each of the three clusters of symptoms (coefficient alpha for reexperiencing is .80, for avoidance .73, and for arousal .70).

As for the test-retest reliability of the CPSS diagnosis, it is moderate with a kappa of .55. The test-retest reliability coefficients of the total severity score and the severity score of the three sub-scales are moderate to excellent (.84 for total severity, .85 for reexperiencing, .63 for avoidance, and .76 for arousal). This scale has also shown very good convergent validity and satisfactory divergent validity. Furthermore, this scale has been previously used with refugee children (Jensen, Skardalsmo & Fjermestad, 2014).

The CPSS can be found in appendix E.

e. Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) is a 25-item questionnaire that was developed to assess strengths and difficulties of children and adolescents between 4 and 16 years. More specifically, the SDQ assesses 5 major areas and can be divided into 5 subscales: a hyperactivity/inattention subscale, an emotional symptoms subscale, a conduct problems subscale, a peer relationship problems subscale, and a prosocial subscale. There are three different versions of the SDQ that can be completed by parents, teachers, or children (between 11 and 16 years old). There are 5 items on each subscale and these items are answered on a 3-point Likert scale ranging from “not true” (scored 0), “somewhat true” (scored 1), to “certainly true” (scored 2). The mean of each subscale is calculated to give a score ranging from 0 to 10 corresponding to the area assessed by that subscale. Adding to that, a total difficulty score can be calculated over 40 by adding up the mean of all four subscales excluding the prosocial subscale. Some evidence shows that in low-risk or general populations, it might be better to divide and score the SDQ according to 3 subscales rather than 5: externalizing problems subscale (which includes the items on conduct problems and the items on hyperactivity symptoms), internalizing problems subscale (which includes the items on emotional symptoms and the items on peer relationship problems), and a prosocial subscale (Goodman, Lamping & Ploubidis, 2010).

In the BIOPATH study, the SDQ was administered to the children’s parent. Externalizing symptoms were assessed by looking at the results of both the conduct problems subscale and the hyperactivity/inattention subscale. In addition to the 25 SDQ items, 12 items were added that match the DSM-5 criteria for conduct disorder (CD) and oppositional defiant disorder (ODD) (sensitive items related to sexual activity, using guns, and setting fires were excluded).

The SDQ has good psychometric properties (Goodman, 1997). First, it has good concurrent validity as it correlates highly with the Rutter questionnaire which is a well-known behavioral questionnaire that has proven to have good validity and reliability. Moreover, the SDQ has good discriminant validity in differentiating between psychiatric and nonpsychiatric samples (.87 for the parental version and .85 for the teacher version). Also, this measure has been translated to Arabic and has been frequently used with Syrian refugees in Lebanon.

The SDQ along with the 12 added items can be found in appendix F.

f. The World Health Organization Disability Assessment Schedule for Children (WHODAS)

The (WHODAS) is a questionnaire that measures disability or functional impairment in children. Specifically, it consists of 36 items that can be divided into 6 sub-scales and assess disability in six different domains: understanding and communicating, mobility, personal hygiene and safety, getting along with people, life activities, and participation in society. This questionnaire has been adapted for settings of low resources (Scorza, Stevenson, Canino, Mushashi, Kanyanganzi, Munyanah & Betancourt, 2013), and has been shortened to 24 items. Examples of items include “In the last month, how much difficulty did you have in keeping a friendship?” and “In the last month, how much has your health condition upset you?”. These items are either scored on a 4-point Likert scale ranging from 0 “no difficulty” to 4 “extreme difficulty or have not been able to do it"; or scored on a 4-point Likert scale ranging from 0 "never" to 4 "always".

The WHODAS has adequate psychometric properties; it has good test-retest reliability (r=.83) and good inter-rater reliability (ICC=.88).

In the BIOPATH study, the WHODAS was translated to Arabic and administered to children.

The child version of the WHODAS can be found appendix G.

g. Distance to clinic

Distance to clinic was operationalized by calculating the distance in kms between the families informal tented settlements and the clinic they had to attend.

h. Time gap

In order to measure the time gap between the date of expressing interest in treatment and the date of an intake appointment, no measure was administered to participants. The variable was operationalized by looking at the date when families in the BIOPATH study have first asked for services and the date when they were called to be informed about being given an appointment. The number of days between the two dates was calculated. In cases where data on these dates was ambiguous, the minimum number of days and the maximum number of days were calculated separately and averaged, giving an estimate of the time gap.

2. For the qualitative component

Qualitative data on reasons for not attending treatment were collected from a purposive selection of children and adolescents, and their parents, from the same pool of pretreatment dropouts described above. Data was gathered by conducting individual semi-structured interviews with caregivers and children. Focus groups were not conducted to prevent violations of confidentiality, as the target group have been identified as having mental health difficulties in a confidential assessment.

a. The semi-structured interview

The semi-structured interview was developed based on findings from the literature and based on clinical experience. Three different versions were developed, tailored for different levels of understanding: one for the caregiver(s), one for adolescents between 13 and 17 years old, and one for children between 8 and 12 years old.

The interview included 5 main parts: i) An introduction which reminds the participant that they previously were interested in treatment, and explores what has changed from that time, and how the difficulties of the young person are perceived now, ii) a section on general perceptions of mental health, which explores the reasons the respondent or other people in his/her environment attribute to the young person's problems, and the way they deal with them, iii) a section on the factors leading to request for services, which includes questions about why the respondent asked for treatment and what he/she hoped to get from it, along with how he/she perceives people who attend treatment, iv) a section on the factors that prevented taking up or continuing the intervention, which includes a set of questions exploring factors that has been shown to be related to dropout in previous literature (examples include concerns about the therapist not understanding the young person, concerns about confidentiality, concerns about how others would perceive them, practical problems, assessment of pretreatment alliance with the case manager who approached them via phone, and problems relating to them being a minority group), and v) a section on suggestions on how to improve the accessibility of the intervention, which explores any comments, feedback, or recommendations the respondent might have. Also, the caregivers' version has an additional final part which asks explicitly about what has been discussed with the young person about his/her problems and about the treatment that was offered. As for the children's interview, it includes additional questions and drawing tasks that aim at making the young child comfortable and more at ease.

The interviews were translated to Arabic and approved by a team who works with Syrian refugees in Lebanon, to ensure that the questions were sensitive to the population.

The interview (including the three versions) can be found in appendices H, I, and J.

F. Procedure

For the quantitative part, all measures have been already administered during the BIOPATH study. No further quantitative data were collected. More information on the collection of the quantitative data can be found in the BIOPATH study (see McEwen et al., 2021a).

For the qualitative part, a sample of BIOPATH participants who expressed a need for treatment (when screened via phone) but who didn't attend the intake assessment or go on to access treatment, were purposefully selected based on the inclusion/exclusion criteria of this study. Families selected were contacted by the interviewer by phone. Initial contact was to briefly explain the aim and rationale of the interview and to schedule an appointment with families interested to participate. When possible, the interviewer made sure that the primary caregiver who showed interest in treatment but then declined attending the intake session is still the same caregiver now, and that the child/adolescent knows that they were offered treatment they did not end up receiving (in line with our exclusion criteria).

All direct caregivers were invited to participate, along with their child, with specific invitation to both fathers and mothers. Also, caregivers and children/adolescents were encouraged to be seen individually with the option of being interviewed together if the family requests this.

Interviews were all conducted over the phone due to road-closures associated with the October Revolution in 2019, and general instability in the country at that time. On the day of the scheduled interviews, consent forms for parents and assent forms for children / adolescents were sent through WhatsApp and were read through together with the interviewer over the phone. Only those who consented / assented were interviewed.

Also, families were asked whether they consent to have the interviews recorded, reasons for recording the interviews, the transcription process, and anonymity were thoroughly explained to them. Families were given the option to refuse the interview being recorded, but to still want to take part in it, in which case a member independent of the research team would be present during the interviews to take detailed notes. However, this case did not take place as all participants agreed to be recorded. At the end of the interviews, participants were debriefed and given the contact information of

MdM again to ensure that they know they can contact the association again in case they wanted treatment or help.

The interviews were conducted by a graduate clinical psychology student who has received training in qualitative research and interviewing by Dr Kristin Hadfield, QMUL, and conducted interviews with the supervision and support of other members in the team. Interviews were recorded using a phone. Audio recordings were stored securely on a password protected computer, transcribed, and deleted after quality checking.

G. Ethical Considerations

The BIOPATH study from which data is derived was approved by the Institution Review Board (IRB) of the University of Balamand (UOB) and the t-CETA study was approved by the IRB at the American University of Beirut (AUB) (protocol number SBS-2018-0582). This study was approved as an amendment by the IRB at AUB (SBS-2018-0582D).

Caregivers were given consent forms which were read through together via phone and questions were answered to ensure informed consent. Since this process was done through the phone, an independent witness, who the family chooses, was asked to be present with the participants during the consent process, and verbal consent was taken from caregivers and from the witness. Caregivers were then sent via WhatsApp all forms signed by the interviewer. The same process was followed for adolescents/children assent forms.

The English forms of the consent form, and the two assent forms (for two different age groups) can be found in appendices K, L, and M.

H. Data Analysis

For the quantitative part, data was analyzed using SPSS v25. First, all variables were explored using descriptive statistics. Second, preliminary analyses for missing values and assumptions of inferential statistics were conducted. Third, binomial logistic regressions were conducted with the binary dependent variable being pretreatment dropout (as compared to the reference group of all participants who did attend and start treatment). The independent variables in our analyses were age, gender, symptom profile (operationalized through four variables: depression, anxiety, PTSD, and externalizing problems), functional impairment, socio-economic status (operationalized through three variables: job classification, cash assistance, and literacy level), time gap between expressing interest in treatment and being given an appointment, and distance to the clinic. Five models were run to dissect these independent variables. The first model included the symptom profile variables; depression, anxiety, PTSD, and externalizing problems. The second model also included functional impairment. The third logistic regression model included the demographic variables, age and gender, in addition to the socio-economic variables: job classification, cash assistance, and literacy level. The fourth model included distance to the clinic, and the final fully adjusted model included time gap.

For the qualitative part, all interviews were transcribed verbatim and translated from Arabic to English. 10% of transcriptions and translations were checked by a second member of the research team. The English transcriptions of the interviews were analyzed through thematic content analysis (TCA), following common standard practice in qualitative analysis (Braun & Clarke, 2006). First, transcriptions were coded by one member of the team (EH), and 10% of the coding was also checked by a qualitative researcher in the team (KH). The next stage of analysis consisted of compiling the codes of all interviews, and re-ordering them in groups based on similarities/patterns of content. Next, potential themes and sub-themes were identified from the ‘groups’ created by EH. Identifying potential themes and sub-themes was done through discussions between two members of the team (EH and TB). The resulting themes and sub-themes were refined throughout the different stages of analysis, and at the end, two other members of the team reviewed the findings (KH and FM). Throughout the entire process, any disagreements were discussed and agreed on by consensus.

CHAPTER IV

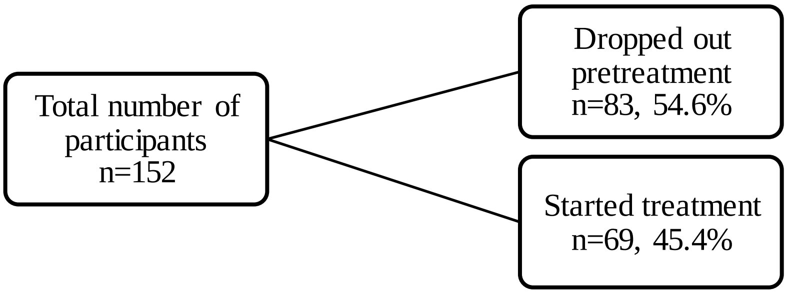
RESULTS

A. Quantitative Part

1. Sample Characteristics

In year 1 of BIOPATH, 197 participants expressed still wanting treatment. In year 2, this number was reduced to 152 participants. Our analyses consisted of year 2 data and sample size. The sample size consisted of 152 participants, 83 (54.6%) dropped out and did not attend the intake session, and 69 (45.4%) attended the intake session (see figure 2).

Figure 2. Sample Attendance Distribution



Child participants were divided almost equally based on gender 77 were male (50.7%) and 75 were female (49.3%). Their ages ranged between 8 and 18 years old, with a mean of 11.79 (*SD* = 2.14). Caregivers were predominantly females (*n* = 147, 96.7%) with only 4 fathers included (3.3%). 32 families (21.1%) reported not having anyone in the family who is able to read or write, 41 (27.0%) reported having members who are able to read and write a little, 42 (27.6%) reported having family members who more or less can read and write, 16 (10.5%) reported having members in the family who can mostly read and write, and 21 (13.8%) reported having family members who absolutely can read and write. In terms of previous job, before the war in Syria, 51 caregivers (33.6%) reported previously working as a manager, a professional, a supervisor, a clerical, a skilled manual worker, or a service or sale worker; 76 (50%) reported previously working as a semi-unskilled worker; and 17 (11.2%) reported never working or having been unemployed for a long period of time. Eight (5.3%) participants did not provide information on their previous work. In terms of cash assistance, around half of the sample (*n* = 78, 51.3%) reported receiving higher than 151$ in the last month, and 69 participants (45.4%) reported not receiving any cash assistance.

Number of children in the families ranged between 1 and 11 children with a mean of 4.86 (*SD* = 2.06). The mean score of depression in the sample was 9.48 (*SD* = 7.99) which indicates a borderline level of depression in the sample. The mean score of anxiety was 15.31 (*SD* = 7.23) which indicates high levels of anxiety in the sample. The mean score of PTSD was 17.79 (*SD* = 15.17) which indicates the presence of high levels of PTSD in the sample. The mean score of externalizing problems was 14.87 (*SD* = 7.00) which indicates marginally low levels of externalizing problems in the sample. In terms of impairment, the mean of the global disability score was 23.02 (*SD* = 2.26) which indicates a high level of severe and impairing mental health problems in the sample.

As for the waiting time between expressing interest in treatment and getting an appointment for an intake session, 29 participants (19.1%) had to wait for a short period of time (between 0 to 6 months) for an intake session appointment, 58 participants (38.2%) had to wait for moderate period of time (between 6 and 12 months), and 35 (23.0%) participants had to wait for a long period of time (longer than 12 months). The mean of the distance in kilometers between the participants' informal tented settlements (ITS) and the clinic was 13.61km (*SD* = 8.34). Descriptive statistics of all variables used in our analyses are shown in Table 1 below.

Table 1. Descriptive Statistics

Variable	N	%	M	SD	Range of scale
Gender					
Male	77	50.7			
Female	75	49.3			
Age			11.79	2.14	
Literacy Level					
Is not able to read or write at all	41	27.0			
More or less reads and writes	42	27.6			
Can mostly read and write	16	10.5			
Can absolutely read and write	21	13.8			
Job Classification					
Manager, professional, supervisor, clerical, skilled manual worker, or service or sale worker	51	33.6			
Semi-unskilled worker	76	50.0			
Never worked or has been unemployed for a long period of time	17	11.2			
Cash assistance					
Receives cash assistance	83	54.6			
Does not receive cash assistance	69	45.4			
Depression			9.48	7.99	0-30
Anxiety			15.31	7.23	0-30
PTSD			17.79	15.17	0-54
Externalizing Problems			14.87	7.00	0-74
Impairment / Global Disability			23.02	2.26	0-100
Time Gap					
Short time gap[1]	29	19.1			
Moderate time gap[2]	58	38.2			
Long time gap[3]	35	23.0			
Distance to clinic (in Kms)			13.61	8.34	

[1] 0-6 months
[2] 6-12 months
[3] More than 12 months

2. Missing Values Analyses

Eight participants did not provide information on their previous job. Information on the distance between participants' ITS and the clinic was missing for one participant, and information on the time gap between expressing interest in treatment and being called for an intake appointment was missing for 30 participants. Participants with missing values were excluded from logistic models that included the variables for which they have missing values, but they were included in model that did not include these variables.

3. Assumptions of Binomial Logistic Regression

All assumptions of logistic regression were examined prior to conducting the analyses. Linearity of the continuous variables with respect to the logit of the dependent variable was assessed via the Box-Tidwell (1962) procedure. A Bonferroni correction was applied using all twenty-eight terms in the model resulting in statistical significance being accepted when $p < .00179$ (Tabachnick & Fidell, 2014). Based on this assessment, all continuous independent variables were found to be linearly related to the logit of the dependent variable. The data was also tested for outliers, and no outlier was found. Finally, the assumption of multicollinearity was tested for by examining the Variance Inflation Factors (VIF) and the collinearity diagnostics. All continuous independent variables had a Variance Inflation VIF value less than 10 (Tabachnick & Fidell, 2014).

4. Binomial Logistic Regression

Table 2 shows all logistic regression models. The first logistic regression model included all participants (n=152) and their symptom measures, and was not statistically significant, $\chi2(4) = 8.0182, p > .05$. The model explained 4.8% (Nagelkerke R2) of the variance in attendance and correctly classified 61.8% of cases. Anxiety and externalizing problems were not statistically significant predictors. Depression was marginally significant in predicting attendance (OR = .958 (95%CI .911 – 1.007). PTSD was a statistically significant predictor (OR = 1.030, (95%CI 1.004 – 1.057), p = 0.025).

The second model (*n* = 152) was adjusted for functional impairment and was not statistically significant $\chi2(5) = 11.979, p > .05$. The model explained 7% (Nagelkerke R2) of the variance in attendance and correctly classified 61.2% of cases. In this model, anxiety and externalizing problems, and symptom severity were not statistically significant predictors of dropout. Depression was also not significant (OR= .960, (95%CI .909 – 1.014)). PTSD was still a statistically significant predictor with the same previous effect (OR = 1.030, (95%CI 1.004 – 1.058), p = 0.026).

The third model was adjusted for demographic variables; age, gender, cash assistance, job classification, and literacy level. This model was missing eight participants and included 144 participants. Similar to the previous two models, the third model was not statistically significant $\chi2(14) = 18.025, p > .05$. It explained 15.7% (Nagelkerke R2) of drop out variance and correctly classified 63.9% of cases. Adjusting for demographic variables slightly increased the effect of PTSD as a significant predictor of attending the intake session (OR= 1.043, (95%CI 1.012 – 1.075), p= .007). All other variables were not significant predictors in the model.

The fourth model was adjusted for distance to clinic and included 143 participants. This model was also not statistically significant $\chi 2(15) = 18.481$, $p > .05$. It explained 16.2% (Nagelkerke R2) of attendance variance and correctly classified 63.6% of cases. PTSD remained significant as a predictor of attendance (OR=1.044, (95%CI 1.013 – 1.077), p=0.06), and none of the other variables included in the model was significant.

The fifth and fully adjusted model included the time gap variable and 113 participants. This final fully adjusted model was not statistically significant $\chi 2(17) = 11.518$, $p > .05$. It explained 13% (Nagelkerke R2) of attendance variance and correctly classified 59.3% of cases. In this model, PTSD was the only significant predictor of attending intake (OR = 1.044, (95%CI 1.005 – 1.083), p=0.25).

Table 2. Binomial Logistic Regression for Attendance of Intake Session

	Model 1 OR (CI)	Model 2 OR (CI)	Model 3 OR (CI)	Model 4 OR (CI)	Model 5 OR (CI)
Depression	.958 (.911 – 1.007)	.960 (.909 -1.014)	.967 (.909 -1.028)	.967 (.909 -1.028)	.968 (.902 – 1.038)
Anxiety	1.020 (.967 – 1.076)	1.021 (.967 – 1.078)	.990 (.930 - 1.054)	.989 (928 -1.054)	.981 (.912 - 1.055)
PTSD	1.030 (1.004 – 1.057) *	1.030 (1.004 – 1.058) *	1.043 (1.012 - 1.075) *	1.044 (1.013 - 1.077) *	1.044 (1.005 – 1.083) *
Externalizing Problems	1.021 (.973 – 1.072)	1.021 (.973 – 1.071)	1.031(.979 - 1.086)	1.034 (.981 - 1.090)	1.046 (.982 – 1.113)
Impairment		.998 (.977 – 1.019)	.996 (.973 - 1.020)	.996 (.972 – 1.020)	1.000 (.974 – 1.028)
Age			.897 (.747 - 1.077)	.893 (.743 – 1.075)	.952 (.766 – 1.182)
Gender (ref: male)					
Female			1.562 (.714 - 3.418)	1.477 (.665 - 3.277)	1.494 (.608 – 3.675)
Cash Assistance (ref: yes)					
No			1.876 (.823 - 4.274)	1.894 (.817 - 4.392)	1.915 (.709 - 5.175)
Literacy level (ref: not at all)					
A little bit			1.676 (.571 - 4.917)	1.669 (.566 – 4.921)	1.264 (.369 - 4.328)
More or less			.860 (.305 – 2.428)	.852 (.301 – 2.414)	.835 (.257 – 2.715)
Mostly			1.520 (.370 – 6.243)	1.582 (.382 – 6.552)	1.051 (.210 – 5.246)
Absolutely, yes			1.872 (.539 – 6.505)	1.687 (.476 – 5.978)	.840 (.194 – 3.639)

Job classification (ref: professional worker)					
Semi unskilled worker			.590 (.257 – 1.352)	.627 (.272 - 1.446)	.643 (.250 – 1.653)
Never worked / long-term unemployed			.419 (.116 – 1.516)	.438 (.119 - 1.610)	.928 (.225 – 3.829)
Distance to clinic				.990 (.946 - 1.037)	.988 (.938 - 1.040)
Time Gap (ref: short (0-6 months)					
Moderate (6-12 months)					1.820 (.602 – 5.500)
Long (more than 12 months)					1.400 (.425 – 4.614)

Model 1: Unadjusted
Model 2: Adjusted for functional impairment
Model 3: Plus adjustment for demographic factors (age, gender and SES)
Model 4: Plus adjustment for distance to clinic
Model 5: Plus adjustment for time gap
OR odds ratio, *CI* 95% confidence intervals
* $p < 0.05$

B. Qualitative Component

1. Sample Characteristics

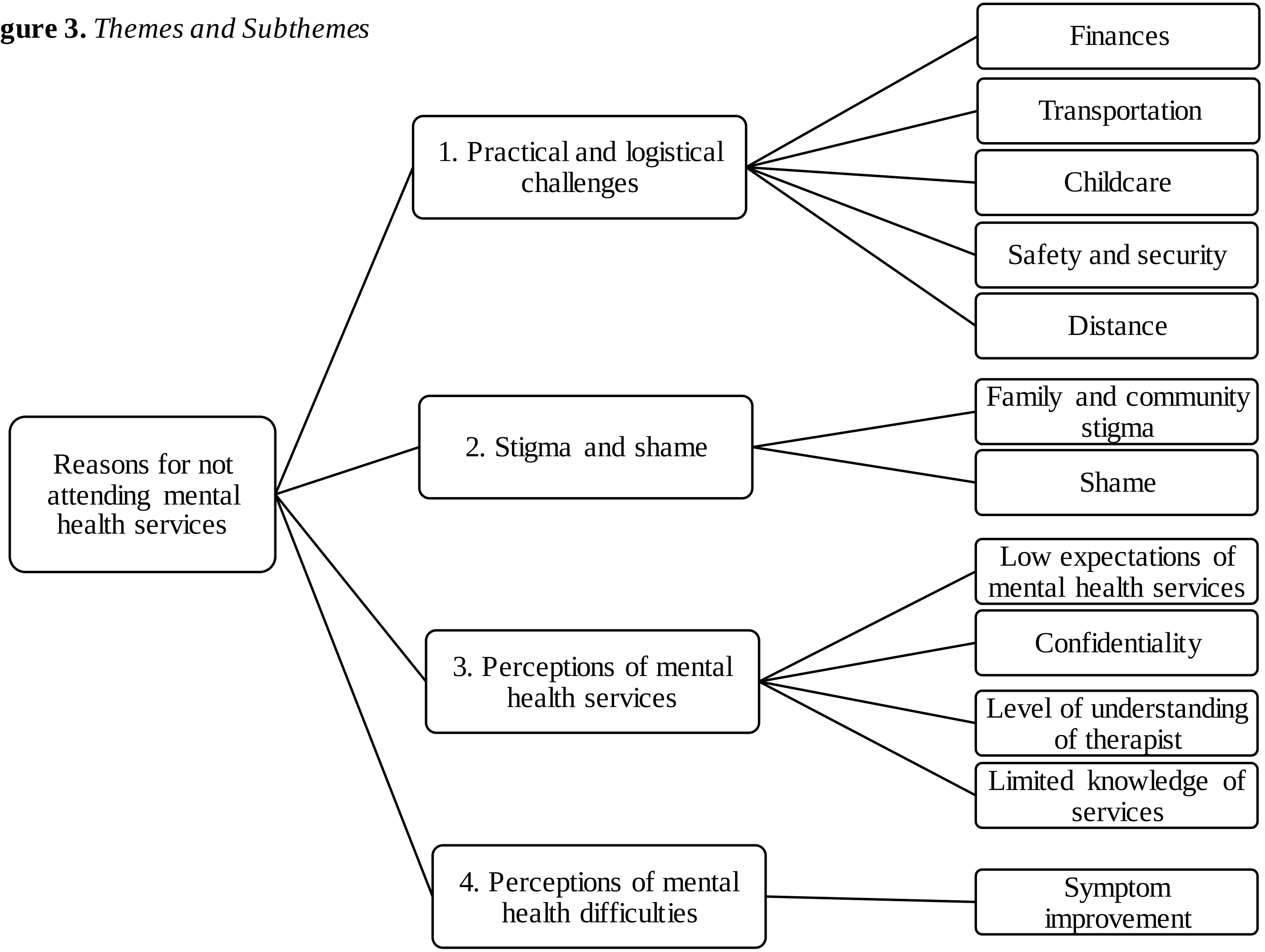
For this analysis, interviews were conducted with nine families. With eight families, the index adolescent and the caregiver(s) were interviewed separately. However, with one family, the adolescent was not aware that they were offered treatment, and was not interviewed, in line with our exclusion criteria. This resulted in only eight adolescents being interviewed. One of the eight adolescents discontinued her participation mid-interview, her answers were still included in the analysis. In addition, with one family, both parents were interviewed together. In another family, the mother and the father were interviewed separately. This is because the mother was the interviewee initially, but due to difference in accent with the interviewer, the mother discontinued her participation, and the father was interviewed instead. Answers from both caregivers were included in the analysis, hence resulting in 2 separate caregiver interviews from this family. This resulted in a total of 11 caregivers taking part in the interview, 8 mothers and 3 fathers.

In total, 18 interviews were conducted with 9 families who were purposefully selected. Children's ages ranged between 10 and 17 years old (M = 13.77 years, SD = 2.28), 5 children were girls (55.55%) with a mean age of 14.6 years and 4 were boys (45.55%) with a mean age of 12.75.

2. Themes and Subthemes

As illustrated in figure 3, a total of 4 themes and 12 subthemes emerged from our thematic analysis. The following section will cover each theme, with its subthemes and excerpts from transcriptions. All identifying information, mainly names, have been either changed or removed to ensure confidentiality and anonymity. Gender and age of participants were kept the same.

Figure 3. *Themes and Subthemes*



a. Practical and logistical challenges

Out of all the factors mentioned and discussed by the interviewees, practical and logistical problems were the most common. In fact, although not all families thought of practical problems as a direct or main barrier to seeking treatment, 8 out of the 9 families (15 out of 18 interviews) reported having at least one of the practical challenges. These included financial difficulties, transportation problems, safety and security concerns, childcare problems, and the clinic being distant and difficult to reach.

i. Finances

Upon being asked about the barriers to taking on the mental health services, most families would directly mention financial barriers, including the finances needed for transportation.

Notably, financial difficulties were discussed as a barrier and a challenge to many critical areas of their everyday life, rather than to mental health support specifically. Families reported financial constraints affecting children's access to education, healthcare (urgent surgeries, medications), and access to food.

> Mother: "And she also has this operation, we are thinking how to do it for her. We promised the one younger than her she needs a device for her leg for like 1000$, imagine […] And he [the father] doesn't have the capacity like half, quarter, of the thing [the amount] that we want to do for her, you know how?"

Two families reported that stress due to financial difficulties triggered a harsher parenting environment which in turn affected the children and exacerbated their difficulties.

In terms of accessing treatment, caregivers and children clearly expressed financial difficulties as a main, and in many cases, the only barrier to seeking treatment.

> 15-year-old male: "I swear what prevented us… is because of the situation, like we have no money and such, everything is expensive".

Similarly, in one family, the 16-year-old adolescent dropped out of treatment not only because they are unable to afford the costs but also because she is working to support the family and, hence, would not have the ability to attend sessions. Six families also believed that securing the costs needed for treatment and for transportation would be a solution that would allow them to engage in treatment.

Two interviews stand out in this subtheme. The first is that of a family in which the female adolescent got married, which she was perceived as an end to her difficulties. In this family, both daughter and mother described that practical problems were not a barrier to seeking treatment. In addition, in another family, the father reported having financial difficulties; however, he did not identify these difficulties as a reason for non-attendance. In this family's case, according to the father, the 13-year-old boy did not take up the services because his problems had completely resolved after his father was able to afford a ball for him and spend time playing with him.

ii. Transportation

Transportation problems were also reported by the majority of families, and 6 out of the 9 families did not end up taking up the treatment due to transportation being a main barrier. For most families, transportation problems were closely linked and interrelated with financial constraints, however, other families had other problems linked to transportation. In fact, the barrier of transportation came up in the interviews as stemming from either financial difficulties (being unable to afford the costs of the trip) or safety concerns (finding it unsafe to leave the camp using taxis or public transportation).

> [Transportation barrier being linked to financial difficulties]: Mother: “For me to go [to treatment] I need to pay 10 or 15 thousand [$3.33, $5 at the time of interviewing] for the car, with this money I would get bread, I would get vegetables, I would get…”
> [Transportation barrier being linked to safety concerns]: Mother: “The problem is that my girls are young […] and me, like it doesn’t suit that I go to Zahle, Sally and I in a taxi alone, […], yes like I can’t, I can’t go out, I risk this adventure and go out, Sally and I to Zahle alone.”

As mentioned in the previous subtheme, all families agreed that securing the transportation and the financial resources needed to attend sessions would solve the barriers for most families who were interested in treatment but failed to attend. Also, and more specific to the transportation barrier, 6 families have suggested having mental health support sessions inside the camp as a solution that would also tackle the main practical barriers.

iii. Safety and Security

In three families and five interviews safety was clearly expressed as a concern that prevents the family from leaving the camp to attend a session. Families had general concerns about safety as well as specific ones. For example, in one family, the 12-year-old daughter as well as her mother separately expressed concerns about the daughter being kidnapped if she were to leave the camp. This fear was triggered by incidents of kidnapping that they were hearing about at the time.

> Mother: “There were talks about a lot of kidnapping. Like the school, they couldn’t go to it. […] I got scared a lot, I swear. I got scared from going to the supermarket and I get scared to go out there and there and I got even scared to take my daughter to the Doctor, I couldn’t unless the car was from here at the camp.”

The daughter also mentioned general fears such as being run over on the road. In another family, the 15-year-old male and his mother had serious concerns about the adolescent’s safety if he were to go to treatment. In this family’s case, the fear was stemming from a sexual assault incident that the adolescent went through inside the camp. Following this assault, the mother feels scared if her son went anywhere outside the house, and she wouldn’t be comfortable unless she or the adolescent’s brother are in his company. The son also added that for him to leave the camp, he would have to pass next to the place where the incident took place, and that scares him.

> 15-year-old-son: “[…] I don’t like to go … I’m scared someone would attack me on the road or something. […] I became afraid a lot, now I don’t pass by this road, when I go, […] I don’t like, when I go in the morning... I don’t like passing by this place.]”

In addition, to concerns specific to families, most women caregivers have implied the safety concern associated with leaving the house, even if not expressed explicitly. This was conveyed by talking about concepts such as women being unable to leave the camp, women being unable to go in a car with a driver who is a stranger, and women being unable to go somewhere without the company or the approval of the husband.

> Mother: ": We didn't participate in the interviews because we had to leave the house and for me to leave the house I wouldn't, do you understand? […] I mean even now my husband was talking to me and telling me to tell you that if they want an interview let them come home or through the phone, and outside the house you don't leave […]."

Similar to the other barriers mentioned above, this concern over safety was shown to be affecting most areas of daily life, rather than one in particular.

iv. Childcare

Three families discussed having young children at home as a reason not to attend sessions, and other families discussed childcare as a concern but not a direct barrier. However, it is worth noting that two mothers explicitly expressed childcare as not being a barrier to leaving the house to attend sessions. The contrast between childcare being a direct barrier and in childcare not being an issue is shown in two excerpts below.

> Mother: "[…] No, I do not have anyone to look after them, no. I swear, they are all little except Sarah, who is older. […] No, it [going to treatment] would cause a problem. I mean, they are little, so to go and keep them at home, or take them with me, is a problem. Do you understand?]"
> Mother: "Yes there was this kind of problem. I have a daughter, but I can secure her with someone if I want to leave. […] Yes, I secure her at my siblings."

In addition, 2 caregivers mentioned being tired and pressured by the many responsibilities they have including raising he children, taking care of the house, and working to provide basic needs for the family. One father believed that some families would not go to treatment as a result of being pressured and busy with little time.

v. Distance

For many families, the distance to the service in Zahle overlapped with the barrier of transportation (not having a car, or not having the costs of transportation). Only one mother reported the distance needed to reach the clinic as a barrier to engage in the offered mental health services. In addition, three adolescents believed that the distance being far could have been one of the reasons that led their parents or other parents to not take up the services.

> 14-year-old--daughter: “Yes, they refused, I mean, maybe the place is far […] I say that it is possible that this is the cause [of dropout], as in, I say because the place is far away, they refused.”

b. Stigma and shame

Besides barriers related to practical and logistical concerns, stigma and shame were the second outstanding topic that was spoken about very frequently in the interviews. Notably, while all 18 participants, caregivers and children, mentioned either the presence of stigma around mental health difficulties and mental health services in the community around them or their own feelings of shame around the topic, this shame and stigma did not necessarily translate into barriers of seeking treatment for many families. In fact, the link between the two appeared to be more complex and nuanced. The section below is a breakdown of the two subthemes that emerged from the analysis.

i. Family and community stigma

As part of the semi-structured interviews, all families were asked about their perceptions and the community's perception of the child's difficulties and of receiving psychological help. Although expected, all participants reported stigmatizing views around mental health around them. These ranged from stigma in the larger community, in their small circles, and in their households and nuclear families. According to the participants, negative views endorsed by the community about people with mental health difficulties included beliefs that the person is "crazy", "sick", that they "talk to themselves" or "have something wrong in their brain", that they are "dangerous" or "scary, and that people should "stay away from them". It was also mentioned that it is common to gossip about a person seeking mental health support, so if one member in the community is aware that the person is receiving help, this piece of information gets shared from one family to the other. Interestingly however, while all participants confirmed the presence of stigma around them, they all reported not having such views themselves. Reflecting on how they would react to someone in the community receiving mental health support, they all reported having either neutral or positive reactions.

In addition to experiencing stigma in the community, some interviewees spoke about being the subject of stigma from close family members; siblings and parents.

> 16-year-old-daughter: "[laughing] she [mother] sometimes says that I am psychologically ill or something like that […] yes and my siblings [too]."

It was also commonly expressed that stigma around the adolescent seeking treatment would not only impact the person but also the reputation of the entire family.

It is important to note, however, that despite the majority of parents and adolescents reporting people around them having negative reactions to the young person attending treatment, two adolescents also reported having close people around them encouraging them. In the first case, the friend of a 14-year-old daughter was supporting her decision to take part in the intervention, in the second case, a 15-year-old son had the support and encouragement of his parents and siblings. Additionally, one mother and one additional adolescent reported that despite the presence of negative reactions, positive ones do also exist in their community.

Similarly, the link between the negative views around mental health and seeking treatment did not appear to be unidirectional. In fact, only 2 out of the 9 families reported fear of stigma as a direct barrier to seeking treatment. In one family, the father of a 10-year-old boy reported stigma and shame around the boy's enuresis problem as the only barrier to treatment.

> Father: "What prevented me is one reason. It is what I told you […] and, it is not the difficulty of me going to a place, because no matter where it is I would go, but I felt that this matter [son's enuresis], it's enough, I mean, I want no one to know about… this is it."

In the other family, the mother of a 14-yead-old daughter reported stigma and financial difficulties as her main barriers.

For the rest of the families, they had different rationales for not considering fear of stigma a reason to not attend treatment. Five families reported that although stigma is endorsed in the community, they simply would not care about what others say, and would not let stigma prevent their children from getting the help they need.

> Mother: “Of course the people will only speak. Of course, the people will speak […] they say that, like the people here wouldn’t say he is checking himself at a therapist and such, they say he is crazy […] of course, it is possible, there are a lot of things that they say, but these people I don’t answer them […] even about the people who speak I am not afraid [of their perception].”

For one family, the mother reported that stigma wouldn’t be a barrier as she would lie to the community about where she is taking her daughter or hide it from others.

> Mother: “No, it [people talking] won’t stop me, I say that... treating her [for a physical/medical condition] like I won’t say psychological... I would say other things […] I can’t let my daughter feel like it’s a psychotherapist.”

For one of the families, the mother believed that although stigma exists, that wouldn’t stop her 16-year-old daughter from seeking treatment as everyone around her have been though similar circumstances and experiences, and children around her have similar problems.

One daughter believed that the barrier of stigma would be solved if parents have neighbors and community members around them encouraging them and explaining to them that therapy would be good to the child and would help them.

ii. Shame

Very closely linked to the subtheme of 'Family and community stigma' is the subtheme of 'shame'. Shame was expressed either about the child's difficulties themselves or about seeking help for these difficulties. In some cases, shame was linked to both. While some families were able to clearly express about and differentiate between shame and guilt, the two concepts seemed to be intertwined. However, an interesting nuance between the two was talking about feeling ashamed as a direct result of the stigma present around them, as opposed to concern about self-shaming (and parents worrying about children's self-shame).

In addition, interviewees were able to express stigma and shame in relation to gender, age, and the type of the problem present. Starting with the gender, shame seemed to increase in both directions, partly due to the type of difficulty. In other words, in one family, the 15-year-old boy and his mother reported that the son receives more stigmatizing reactions from the community due to his gender. On the other, two caregivers reported the level of stigma and shame around their daughter's difficulties being higher due to the fact that the person with the difficulties is a girl. In the first case, the son's main difficulties were feeling anxious and having fears, which did not seem to fit with the schema of a 'manly boy' in the community.

> 15-year-old-son: "Yes, they tell me that I'm crazy, they tell me you are a girl… you're not a man, things like that. You know our society, in our society if you're not one that hits and beats up… it means you're a girl. They make fun of me a lot."

In the two other cases, the daughters with difficulties had enuresis and externalizing problems, which also did not seem to fit with the standards of a 'young lady' in the community. Adding a layer to this distinction, two mothers reported shame being higher because their daughters are 'old'. This, according to them, has an effect on their future and on their chance of getting married.

> Mother: "So, for me... like I get shy to take my daughter to a psychotherapist because people will say that this means something is wrong with her daughter or something […] because in the end she's a girl […] it impacts her future because for us Arabs it impacts her future."

It is important to note, however, that while a third mother also spoke about age and gender being directly linked to an increase in the level of shame around her daughter's difficulties, she believed that this would not impact her marriage in the future. In addition, feelings of shame were clearly expressed in all families with children having enuresis problems, including girls and boys. In the case of a 12-year-old adolescent, the mother reported being ashamed herself of the daughter's problems, being ashamed of disclosing her problem to a doctor, and believing that her daughter feels ashamed about her problem.

> Mother: [answering whether she has thoughts of distancing her daughter from others so that they don't become aware of her problems] "Yes yes yes yes, like a lot, I don't even let my brother's family, who lives next to me, to know. And I even get her pads, so that there is no smell in the tent or something, I tell her to pee in the pad and if she does, to throw it […] sometimes they get shy, that they pee in the pad]."

The concern of disclosing the child's difficulties to a therapist or a medical daughter was shared by another father who believed that his son's enuresis problem is so shameful that it cannot be talked about even with a professional.

Adding another layer to the subtheme of shame, two parents had worries about their children thinking of themselves as 'crazy' if they knew that they were going to a therapist. In these two cases, the two parents expressed that a solution would be lying to their child. In other words, take the child to treatment without letting them know that it is psychological treatment, as an attempt to protect the child from self-shame.

> Father: "I swear we are unable to mention that he has this problem. Do you understand how? […] it is difficult I swear, it is […] I want to keep him away, I mean, and not let the people know that he has this thing […] I swear I want to, I want to go [to treatment], I want to go, but I do not want to tell him, for example I mean that I am taking him to a doctor like that you know how […] I mean I want to try to tell him for some other thing I mean [for something other than his psychological difficulties]."

For one father, shame around the son's difficulties and fear around the son knowing that he is going to treatment for these difficulties were the only barrier to going to treatment.

c. Perceptions of mental health services

Caregivers and adolescents had similar expectations of treatment and similar motivators to express interest in seeking it. The most common aim of treatment, expressed by 7 caregivers and 3 adolescents, was for the child and their psychological state to 'get better' and to 'feel relieved'. Other similar aims were expressed in terms of the child 'feeling comfortable', 'feeling happy', 'feeling safe and content', 'feeling calm' which was compared by a mother to taking medication, and 'getting rid of problems.' A 13-year-old-boy believed therapy makes the person 'feel a nice feeling'.

> 13-year-old-boy: “It [therapy] will help him get better, and help him go back to normal, and make him feel a nice feeling. […] I... I would’ve loved to get better and to keep…, I mean... I mean I didn’t used to laugh. I only you used to constantly think and that’s it.”

Some participants were able to elaborate in more depth on the process of therapy, as a 14-year-old daughter was hoping therapy could help her work on her self-confidence and one caregiver and two adolescent boys were hoping that therapy would help them become more aware of things, and ‘understand more’, touching on concepts of self-awareness.

> Mother: “A person becomes more aware of things […] he holds himself and such stuff. […] A person learns stuff that for example, that helps him organize his household issues, his children, he takes care of his children, for example, their behaviors become better such stuff”.

On the other hand, some motivators to seeking treatment seemed to endorse stigmatizing views, or misconceptions about therapy. One mother believed therapy helps the person go back to the way they were as a child. Another 17-year-old-daughter believed the therapist gives advice to the person on what to do. And one caregiver and an 11-year-old daughter had a more medical view of therapy, by which doctors give medicine to the person who ‘gets cured’ resulting in a decrease in pain.

In line with these expectations of mental health treatment, 5 caregivers reported believing that therapy would have helped their children, and one caregiver reported not knowing whether it could have helped. For 2 mothers, positive expectations of therapy were also related to knowing other people in their communities getting better after receiving mental health support. As for the adolescents, 4 of them believed therapy could have helped with their difficulties, and one 11-year-old girl did not know whether therapy could have helped her. Interestingly, a 17-year-old-girl believed therapy helps other people feel better and work through their difficulties, but that it would not help in her specific case. These positive expectations of treatment were not only expressed about mental health support in general but also about receiving the support of Médecins du Monde (MdM) specifically (the implementing organization), as all caregivers reported seeing MdM as a trustworthy organization. Similarly, caregivers who remembered having the phone assessment call reported being comfortable and at ease with the phone assessor.

i. Low expectations of mental health services

3 participants described barriers to treatment being closely linked to perceptions of services. A 13-year-old-boy believed that other children might not attend treatment because ‘they might have a fear of psychotherapy’. A 14-year-old girl described that other adolescents might want to go to treatment, but their parent’s might not believe in the effectiveness of therapy or need of it, which prevents the young person from going.

> 14-year-old-daughter: “[replying to what prevents adolescent from going to therapy] Maybe their parents […] I mean, for example, their parents say that there is no need, I mean it is enough as in there is no need. Yes, they are like that, they say like that, that therapy won’t benefit them, they think and say that, I mean, how can I tell you that it is unimportant […] because they think that psychotherapy, as in it will not be useful.”

And one mother explained her daughter’s non-attendance by the fact that the therapist wouldn’t tell the daughter anything new that her mother has not already told her.

> Mother: [reflecting on how the daughter would explain her non-attendance] "She [daughter] would say that the things they [therapists] will tell me, my mom would sit and tell them to me."

ii. Confidentiality

Perceptions of confidentiality of treatment were divided among participants. 4 caregivers trusted that confidentiality would be maintained in therapy if their children had taken part in it, and so, had no concerns about it. For one mother, she had no doubt about confidentiality being respected as she, herself, did not know what her daughter spoke about during the assessment session with Médecins du Monde, which she perceived as a strong positive experience. On the other hand, 5 other caregivers and 2 adolescents reported having concerns about the confidentiality of treatment.

> Mother: [concerning confidentiality] "Yes I get scared, these things and cases concern me, like you know who they would be and us, we are strangers, like they might harm him [son] or something."

Interestingly, however, having concerns about confidentiality did not translate into barrier of attendance for most participants. In fact, all caregivers described that these concerns were not barriers.

> Mother: "Like people talk and they talk about people privacies and such things. […] These are concerns they are concerns but they did not prevent us."

Only one out of the 2 adolescents, a 17-year-old-adolescent-girl, described concern of lack of confidentiality as a barrier to her attending treatment.

This pattern seemed to be similar to the link between stigma and barriers of attendance, as parents would find ways around the concerns they have, without these concerns turning into concrete barriers.

iii. Level of understanding of therapist

Out of the 9 caregivers, 7 had no concerns about the therapist not being able to understand their children or their problems.

> Mother: "No of course like a psychological doctor will understand the case of the patient that he is getting."

Although, one mother believed that misunderstanding might happen due to the cultural differences between the therapist (being Lebanese) and the daughter (being Syrian) as ''our situation differs from theirs', she described that this would not be a concern nor a barrier.

Notably, one mother had a concern about the daughter misinterpreting what the therapist would say, and in turn, thinking of herself as crazy, which goes back to the concept of self-shame previously discussed.

> Mother: "I trust that the psychotherapist would understand Wared and understand her problems but scared that Wared wouldn't understand them. […] I fear that she misinterprets it […] Like she feels like she is crazy, or something is wrong with her or something like that there is something wrong with her".

For the other 2 caregivers, they described having concerns about the therapist's ability to understanding their children. For the father, this concern was directly linked to the son having enuresis, which was perceived by the father as very shameful, and difficult to talk about even with a professional. For both caregivers, however, this concern did not translate into barrier of attendance.

One case stands out in this subtheme; a 17-year-old-daughter reported her concern of the therapist's inability to understand her problems as the main barrier to her non-attendance. This adolescent believed that the therapist would find her problems to be insignificant and could laugh at her. Although she had other reasons such as fear about the confidentiality of treatment and concern about people's perception, she described that the possibility of the therapist making fun of her was the main reason for nonattendance. She also believed that other adolescents might not go to treatment out of fear of their problems being perceived as odd.

> 17-year-old-daughte: 'Like, he wouldn't understand me. That he would feel that it's [my problems are] normal, that everything that I am telling him is normal [not a valid problem]. […] I felt like the doctor would laugh at me […] I mean, the problem would be trivial/insignificant, or something like that according to him. […] or that he doesn't understand me".

iv. Limited knowledge of services

Limited knowledge of mental health services was a salient trait in the interviews, although not necessarily expressed explicitly by interviewees. 2 adolescents and 2 caregivers reported not knowing how therapy could have helped with their difficulties. One of these caregivers, a father, also reported not knowing what psychotherapy is or its purpose. Limited knowledge of services was also shown more implicitly, as caregivers would provide somewhat vague answers and find it particularly difficult to elaborate. For example, one mother didn't really know what to expect from treatment but thought she would still give it a try.

> Mother: "Like I don't know I said maybe that… something comes out of it, for example… like this is what I mean you (plural) calm her down with something or you (plural) speak to her, like this is it".

Additionally, 5 caregivers reported that their children had positive experiences with an assessment session which was conducted with them prior to treatment. Short interventions, such as one assessment session, could have therapeutic effects as they allow the person to have a safe space to disclose sensitive information and to feel validated and heard. However, this assessment session seemed to be confused as being therapy, with poor understanding of the difference between the two. For example, one mother believed her daughter's problems got resolved after the assessment session, even though the assessment was only the first meeting before starting therapy.

> Mother: [replying on what were her expectations if her daughter took part in therapy] "I swear like if God wills, that the psychological state, that Samira changes. and that… thank God just what I was expecting happened, thank God. [talking about the assessment session] Yes… after the guys came and they met with Samira and they stayed about an hour, an hour and a half, the girl sat with Samira and Samira spoke to her, even I don't know what Samira spoke to the girl till now. After it I felt Samira's psychological state bit by bit started changing. Even once they came here to the house and Samira was present here in my house so we went out to them and she told them thank God my situation became good, my situation… like I am not in need of anything now thank God […] Like no medication and no nothing and Samira's psychological state felt better, I feel she got better after the guys left the same day and the following day and due to talking… Like Samira changed, changed."

This pattern was also present with other participants. One 16-year-old-daughter reported already taking part in therapy, then proceeding to elaborate on the assessment session. And two other caregivers appearing to consider one-off psychosocial support as equivalent to psychotherapy, such as a lecture given on enuresis and a one group support session.

Additionally, in two families, caregivers reported people in their community misrepresenting their children's need of therapy as an attempt to receive financial support if the child takes part in the service.

> Mother: "I know people… […] some people are not in need of these things but when it includes money, they do it, you know how? For example, ah… pardon me for that word, there are people who are not in need of this like psychological treatment and such but when they heard it includes paying money, they started doing it you know? […] Like they have the thousand like it does a lot, you know? [meaning: a small amount of money would make a big difference to them]"

According to the father who spoke about the same concept, misrepresentation of the child's need can in itself be direct a barrier to treatment, as the family doesn't end up taking up the services when it doesn't match the financial benefit they had in mind.

> Father: [Replying on what are the barriers that prevent other people in his community from going to treatment] "Miss I swear for example either their parents don't have the time, or they are busy or something like that, or they are liars, or they are liars. […] The children miss wouldn't have anything [anything medical or psychological that requires services]. [But parents misrepresent their children's case] so that they take support for example."

Closely related to limited knowledge of services, 3 adolescents and 1 caregiver believed that providing psychoeducation to families about how therapy works and what to expect out of it can be a solution to the barriers of starting treatment.

> 15-year-old-son: [replying on how to solve the problems that stop people from starting treatment] “We should encourage them by telling them that the person that goes to a therapist is not crazy, a lot of people need a therapist. Anyone who makes fun and says that therapy is for crazy people is actually the one who needs therapy. […] I support them, tell them yes.”

d. Perceptions of mental health difficulties

Although the reasons attributed to the young person’s difficulties deferred slightly from family to another, with some cases being unique, reasons expressed were similar in most families. These reasons attributed to the difficulties were not directly linked by caregivers and adolescents to the reasons of non-attendance, however, they are worth mentioning as they add a layer of understanding of these problems, indirectly affecting the take up of services.

First, 4 caregivers and 2 adolescents linked the mental health difficulties to the hardships they went through in Syria. This included experiencing traumatic events in Syria as well as during displacement. For one specific family, this was also linked to the father being imprisoned and separated from his children for a few months.

> [Incidents in Syria] Mother: “No, not recent, she has this [mental health difficulties] from a long time ago, since the days of the incidents [in Syria] and on, since the incidents and on. [Reflecting on the reason behind these difficulties] Fear between the fear. I mean we, the grown-ups, were scared, how would she, when they broke into our house, and like that… they did this and this to us, she got scared.”
> [Incidents during displacement] 15-year-old-son: “[explaining the reason behind his fears] I swear, I get scared... Something also happened to me

> once when we were in Syria. Maybe I told you (plural) before, when we were… we went from place to place, there were missiles in this place, they threw bombs during the war. A rocket came and fell in a region a bit close to us, 40 people were killed, all their arms were hanging on the electricity chords, and their heads… I mean… extremely frightening scene. A lot of blood on the floor, a lot of people died. We passed by them so we could run … this region."

In this regard, only one father who reported not knowing what the reasons are, also expressed that he does not think the circumstances they lived in Syria played a role.

In addition, another highly common reason attributed to the difficulties was the current situation in Lebanon. This included children not going outside the house - often described as 'imprisoned' or 'locked up' in the house - not going to school, not having friends to play with, having severe financial difficulties, and living in poor conditions. This was described by 6 caregivers and 3 adolescents.

> Mother: "[..] Because before in Syria, I have 6 girls. Yes like I have 6 girls. I swear 6 girls and Yasmine is one of them. And I didn't have any problem at all and, not the anger and not the… that all of it. Like we were living a life, no one gets angry at anyone, and no one gets mad at anyone, maybe that this anger and these worries and these problems we got to them in this move from our country and in these camps and these… [..] I swear ever since we left our country the psychological states in children and in adults became all tired. […] From this life that we are living sometimes there is no water sometimes like we want… the camp how we're living, a life I swear to God we don't get envied over it at all."

In term of financial difficulties, parents explained the link to mental health difficulties in two ways. First, children are facing psychological difficulties due to not being able to get things they want. According to one mother, this is exacerbated by her daughter going to school, as she sees her friends buying new things and she compares herself to them, but her parents cannot afford to buy her what she wants. And second, financial difficulties affect children indirectly by stressing parents who feel pressured and resort to harsher ways of parenting.

> Mother: “In general, I mean for example I am telling you about the situation every month, I mean, when they want something […] like they want something for example from the… they buy it like for example, no? […] I do not have the ability to buy them anything, I mean, I mean I want to buy. I have four children I want to buy for one and let one become angry and become frustrated. This is our problem; I mean with the inflation and such… Yes, and this is becoming a problem. I mean a lot a lot of anger and the children are being raised with this anger... […] A lot, a lot, my mental state is poor. I swear my mental state is poor over the inflation and such, I mean the child wants to buy and I do not have, I don’t have the ability of buying, even if he starts hitting or starts getting angry.”

Other reasons described in co-existence with the ones mentioned above are being young, children witnessing problems between their mother and father, and having a harsh father.

Only one family stands out in the reasons attributed to the difficulties, as a mother and her 13-year-old-son described his difficulties being the result of having an emotionally and physically abusive grandfather.

i. Symptom improvement

Parents and adolescents had different perceptions on whether the young person’s difficulties were still present at time of the interview or not. Six caregivers perceived their child’s difficulties as still being present, with different thoughts on the reason behind the difficulties increasing or decreasing. For the 4 other caregivers, psychological difficulties were believed to have gone completely. However, with further elaboration these caregivers described problematic symptoms still existing, but these symptoms were not perceived by the caregiver as being related to mental health or requiring an intervention. For example, one mother believed that her daughter's psychological difficulties have resolved and that now she only has anger.

> Mother: "No thank God like she is not sick psychologically for me to be worried about her or to be worried that people talk about her, no… but like just anger."

In this case, behavioral difficulties were not perceived as psychological. In another family, the mother believed that her daughter got better, and that no intervention was necessary because her difficulties - nightmares, sleep talking, and sleepwalking – occur only at night, which was also linked to a lower likelihood of the neighbors knowing about these problems.

> Mother: "No, we did not do anything because she only talks when she is sleeping. When she is sleeping, we do not do anything, but she begins to scream, do you understand how? I mean nothing is in our hands, I mean […] if she has problem while she is awake, yes, we would have taken her to treatment. I mean."

In addition, a father described that his son has been 'completely cured' and has no more psychological symptoms. The 13-year-old-boy in this family had (emotional) depressive symptoms (sadness, crying, isolation) which were in fact resolved. However, although the adolescent was still experiencing physical symptoms of depression as he was struggling to sleep and was not eating well, these remaining symptoms were perceived as medical and not related to the depression.

> Father: “Miss thank God he recovered from them [the psychological symptoms], recovered from them. He just has something miss, a bit of laziness, of course weakness in… in the body only. […] Yes [his symptoms are] physical. […] He does [have medical issues] I swear Miss. He doesn’t eat, he doesn’t drink, he doesn’t sleep. Just that. [Discussing the reason behind the son’s physical symptoms] I don’t know I swear Miss. We went to the doctors, in tests [blood tests] there is nothing, I did analyses for him, he [the doctor] told me there is nothing. I took him to the Doctor, I did some tests for him, the doctor told me that there is nothing and that his body is weak.”

In fact, the father’s perception of the psychological difficulties being completely resolved was the main and only reason for not attending treatment. In addition, another family had similar reasons not to attend treatment. The 17-year-old-girl and her daughter both described that the daughter’s difficulties – anxiety, sadness, and loneliness – resolved after the adolescent got better. According to the adolescent, she used to have these difficulties because she rarely used to get out of the house, and she did not have people around her to talk to. However, after getting married, she gained a social network that helped her overcome these difficulties, and in turn, there was no longer a need for treatment.

> 17-year-old-daughter: “No, I mean, these problems are gone. I no longer have shyness, nor do I have anything else. Nor fear and no… […] They are completely gone. [replying to the reason for her difficulties resolving] I got married and I felt like everything changed]. […] Because in the beginning of the marriage, people started coming over. People used to go with me… yes, I felt that there was something that changed a lot in my life.”

CHAPTER V

DISCUSSION

A. Summary of findings

The aim of this study was to examine predictors of pretreatment dropout in a sample of Syrian refugee children and adolescents in Lebanon, and to qualitatively explore in depth the reasons for non-attendance. This is the first study, to our knowledge, to examine pretreatment dropout in a humanitarian setting in the Arab world, and to use a mixed-method approach.

Results showed that only levels of PTSD predicted treatment attendance as higher levels of PTSD were associated with higher likelihood of attendance. Content analysis of 18 interviews yielded 4 themes and 12 subthemes of treatment non-attendance. Themes were around practical and logistical challenges, stigma and shame, perceptions of mental health services, and perceptions of mental health difficulties.

B. Quantitative component

Our findings show that neither age nor gender predicted pretreatment dropout. Consequently, our first two hypotheses are rejected. To note, the available literature has mixed evidence in terms of age and gender as predictors of dropout, with some studies showing no significant effect (for age, Werbart & Wang, 2012; for gender, Killaspy, Banerjee, King & Lloyd, 2000), others showing an effect in one direction, and other studies showing a significant effect in the other direction (for age, Baruch, Vrouva & Fearon, 2009; for age and gender, Werbart & Wang, 2012). In other words, our hypotheses about age and gender predicting dropout are not supported by our findings, however, our results are in line with other studies in the literature showing no significant effect of age and gender on dropout. In terms of age, a meta-analysis of 115 international studies has also found no significant effect in predicting dropping out (Fernandez, Salem, Swift & Ramtahal, 2015).

We also hypothesized that symptom profile (depression, anxiety, PTSD, and externalizing problems) would significantly predict pretreatment dropout. In the partially adjusted model, results showed that anxiety and externalizing problems did not predict dropout. As for depression, lower levels marginally predicted intake attendance when the model only included symptom profile. However, this effect was no longer there in the partially adjusted or fully adjusted model, indicating that other factors better explained this association. On the other hand, increasing levels of PTSD remained associated with an increased likelihood to attend the intake session in all 5 models, with the effect remaining almost the same. Therefore, our third hypothesis is rejected. Furthermore, and contrary to the hypothesized direction, increasing levels of PTSD were linked to treatment attendance rather than dropout. The literature on symptom profile has inconclusive findings overall with some studies showing a specific disorder as a significant predictor of dropout (for example depression and eating disorders, (Fernandez, Salem, Swift & Ramtahal, 2015)), and other studies showing no such effect.

As for functional impairment, we hypothesized that higher impairment will significantly predict pretreatment dropout. However, functional impairment was not a significant predictor and had no significant effect, which disconfirms this hypothesis as well.

In terms of socio-economic status, we predicted that families with lower SES would be more likely to drop out of treatment. This was measured through looking at job classification, literacy level, and cash assistance. However, this hypothesis was rejected by our analyses as none of these variables significantly predicted dropout. In order to explain this finding, the distribution and variance of the variables used to operationalize socio-economic status are important to consider. While we hypothesized that lower SES would predict pretreatment dropout, such effect was not found in out analyses. However, studies in the literature showing the presence of such an effect compare people from relatively high SES to others from low SES. In fact, being from an ethnic minority group and having lower socio-economic status are the only consistent predictors of pretreatment dropout in the literature (Swift & Greenberg, 2012; Barrett et al., 2009; Topham & Wampler, 2007). In our case, however, our population is refugees, hence a minority group, and while we did find some variability in the different measures, all participants are considered to be from low socioeconomic statuses, with different degrees. This can be backed up by the qualitative interviews, as all nine participating families reported having serious financial difficulties. This can also be seen through some of the available measures in the data. For example, we had initially planned to use both food assistance and cash assistance as two predictors of dropout, each one of them operationalized in 6 different categories. After running descriptive statistics on our data, the distribution on these two variables was very poor, with most participants falling in one or two categories, and some categories having 0 participants. To deal with this, we ended up excluding food assistance from the analyses and using cash assistance as a binary variable with only two categories (yes/no). These redistributions lower our ability to detect significant effects. Furthermore, the context is important to consider in our interpretation. Data collection for BIOPATH occurred at the beginning of an unprecedented economic crisis that plunged three-fourths of the population under the poverty line, leaving those already struggling in terrible hardships (Malik & Haidar, 2021). With such a population and a context, all participants are considered from critically low socio-economic statuses.

Similarly, we hypothesized that the time gap between expressing interest in treatment and getting an appointment would predict pretreatment dropout. However, the effect of time gap on dropout was not significant in our analyses, and so, the hypothesis is rejected. To link this finding back to the literature, while some studies found the time gap as a significant predictor of dropout (Barrett et al., 2009), other studies have in fact found this variable to be non-significant (Killaspy, Banerjee, King & Lloyd, 2000). And so, while our finding rejects our hypothesis, it also goes in line with the findings of other studies in the literature.

Finally, we hypothesized that longer distances needed to reach the clinic would predict dropping out pre-treatment, no such effect was found in our study. The last and seventh hypothesis is also rejected.

Based on the quantitative analysis, all of our hypotheses were rejected. Only symptom profile, specifically PTSD, was a significant predictor of intake attendance, contrary to the direction we hypothesized. This provides strong support for the impact of traumatic symptoms and experiences on attending much needed mental health support. While none of our other hypothesized variables predicted dropout in our sample, various other factors might have played a role in our results and should be taken into consideration in interpreting and drawing definite conclusions. In addition, our qualitative analysis and results can help interpret and better understand some of the unexpected quantitative findings.

A number of factors pertaining to the methodology, some of which overlap with the limitations of the study, are important to highlight and consider and can help explain the findings. Firstly, for the purpose of this study, we used pre-existing data from the BIOPATH study (see McEwen et al., 2021a) and conducted secondary analyses on it. While secondary data analysis has the advantage of saving significant time for researchers and families, maximizing the use of existing datasets, and answering research questions derived from on-the-ground realities; it also has important drawbacks, some of which could affect the validity and reliability of the measures used in the analysis (Vartanian, 2010). The data collected through the longitudinal BIOPATH study had different aims and objectives, and so, variables were not operationalized and tailored to the purpose of analyzing dropout. The variable on time gap between expressing interest in mental health treatment and being given an appointment for a session can be used to better illustrate this point. As the literature includes some studies showing time gap to be a predictor of dropout, we were interested in including it and testing it in our sample. However, as this variable was not one of the variables of interest in the BIOPATH study, information around it was not systematically collected. We created this variable by looking at any date of contact mentioned for each family. However, in many cases there would be no mention of date, or no clear description. To deal with this, two separate members of the research team examined and came up with the time that shows the gap independently, then any disagreements were discussed. However, this process still included some subjectivity in a few cases, and led to missing data for 30 participants, substantially reducing our sample for the model including this variable. In this regard, multiple imputation could have helped in reducing missing data in our analysis.

Theoretically, and besides methodological factors, the literature available on dropout should also be considered as conclusions are drawn from our analyses. In fact, the evidence on age, gender, symptom profile, and time gap are all inconclusive. Two major limitations of the literature stand out and help in explaining the discrepancy: inconsistent operationalizations of dropout and the lack of differentiation among the different stages of dropout (Fernandez, Salem, Swift & Ramtahal, 2015). It can be hypothesized that the discrepant findings in the literature are linked, at least in part, to different studies operationalizing dropout differently. As an example, it can be misleading to compare predictors of dropout in a study in which dropouts were selected based on clinical judgment (Swift & Greenberg, 2012) to predictors of dropout in a study in which dropouts were selected based on a certain statistical change in symptoms at point of discontinuing treatment (Bados, Balaguer & Saldaña, 2007). Similarly, reasons to discontinuing treatment vary on the stage of dropout. In other terms, those who express interest in treatment but don't go on to attend the first session can have different barriers compared to those who started treatment but left after the first session or those who left after a few sessions. This, again, makes is misleading to compare results from one study to the other, and could help in explaining some of our results which are not in line with the existing literature.

C. Qualitative component

1. General Discussion

The aim of our semi-structured interviews was to explore in depth the reasons for pretreatment dropout after having expressed interest in treatment. Our content analysis revealed 4 themes and 12 subthemes. Our themes included practical and logistical challenges, stigma and shame, perceptions of mental health services, and perceptions of mental health difficulties.

Initially, it is important to differentiate between concerns reported by participants as opposed to reasons for non-attendance reported. In fact, although participants had multiple concerns around the young person attending treatment, many of these concerns did not translate to direct barriers, as parents and children were able to find a way around them.

The first and most common theme to emerge from our analyses was practical and logistical challenges. These challenges in attending treatment included financial and transportation difficulties (including distance to clinic), safety and security concerns, and childcare responsibilities. All interviewees described struggling with major financial difficulties making it difficult to attend mental health sessions. This theme shows that there is a gap between the services offered to the refugee population and their needs and priorities. This gap can be better understood through the blackfoot model of beliefs (Feigenbaum & Smith, 2020).

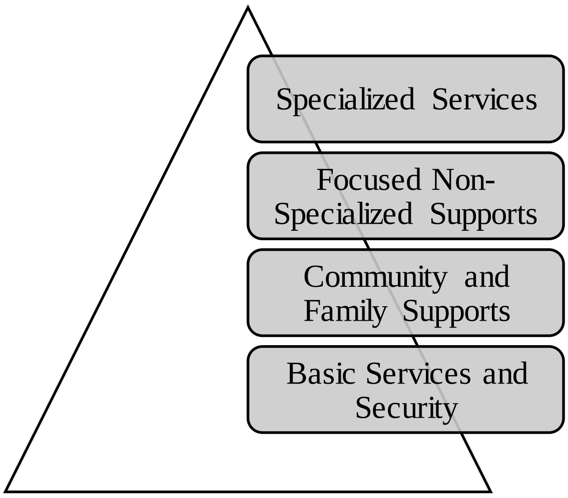
In fact, and going back to refugees' contextual background in Lebanon with the multiple crises taking place, families have concerns about basic human needs to ensure sustainability. In this regard, it is reasonable for families to prioritize their resources for physiological and safety needs and to perceive mental health difficulties and services as less imminent.

As suggested by participants, solutions that could help with these barriers are compensating for transportation costs and providing free services. Similarly, it can be suggested that integrating social work with the psychotherapeutic services provided can increase uptake of services. This further demonstrates that refugees would be more interested and capable to engage in mental health support when their basic needs are met.

The second theme commonly present in our analysis is stigma and shame. This included stigma endorsed by the host community, by close neighbors and family members, and self-shame. Stigma also appeared to be highly impacted by age, gender, and the type of difficulty. In specific, stigma, shame, and self-shame were notably high when the child with difficulties had enuresis. Although concerns around stigma and negative perceptions were common, these concerns were not direct barriers for most families.

Participants also had suggestions on ways to prevent stigma from being a reason for nonattendance of services. These included having mental health support sessions inside the camp. The Inter-Agency Standing Committee (IASC) model can help better understand these concerns and translate them into possible implications (Snider & Hijazi, 2020) (see figure 4).

Figure 4. The IASC Guidelines Pyramid



In fact, with communities endorsing high levels of stigma, interventions should be grounded in the community itself. The literature shows that focusing on traditional psychological interventions in dealing with refugee populations has significant limitations. In humanitarian settings, a more holistic-community based approach is warranted in which support is multi-layered, culturally and contextually appropriate, and building on the existing resources of the community (Jordans, Pigott & Tol, 2016). Adopting community-based models in which community members are active agents in the different stages of implementing an intervention can help reduce the stigma and strengthen the role of the community as a supportive and protective entity. Specific to the stigma around enuresis, these interventions can also help in community desensitization, allowing for less shame and a higher possibility of providing the young person with the help required.

Perceptions around mental health services was also a theme of concerns and possible barriers in our analysis. While some concerns were specific such as being concerned about confidentiality or about not being understood by the therapist, limited knowledge of services appeared to be a major barrier, affecting uptake of services in implicit as well as explicit ways. At various instances during the interviews, caregivers and adolescents seemed to lack a clear idea of the services they were offered. As an example of this, families described caregivers in the community expressing interest in mental health interventions when children are in no need for such interventions. This was explained by caregivers struggling with serious financial difficulties and hoping for these interventions to provide the family with assistance or compensation. This theme of reporting false positives as a result of poor living conditions and desperation has been also found in a qualitative study examining challenges of administering a structured clinical interview to adolescent Syrian refugees in Lebanon (Kyrillos et al., in press).

As caregivers and children have suggested, psychoeducating families about mental health difficulties and mental health services is key. In fact, our analysis shows that extensive psychoeducation is required in order to ensure that families know what they are taking or not taking part in. This would not only inform caregivers' decisions but would also tackle limited knowledge and misconceptions about the difficulties and their reasons which would in turn decrease stigma and shame associated with them.

In line with this, our last theme included perceptions of mental health difficulties. Among the different levels of understanding of psychological difficulties, some were notable in that they can lead to not engaging in treatment as a result of not perceiving a need for such services. For example, many families perceived behavioral difficulties as valid and requiring an intervention as compared to emotional difficulties being seen as less serious and not requiring any services. Families also had unique criteria that shifted their perceptions on whether an intervention is needed or not, such as symptoms occurring at night being less problematic as compared to ones that happen during the day. This is consistent with the literature showing that low perceived need of treatment can be a barrier to accessing services (Karam et al., 2018).

2. Reflections

As the process of content analysis allows for some level of flexibility and subjectivity, reflections around this process and around conducting the interviews can help maximize transparency (Braun & Clarke, 2006).

First of all, conducting the interviews over the phone had its own challenges. Trust was more difficult to build in a short phone call that lacks the ability of seeing and connecting with the other person. In this regard, agreeableness and social desirability might have played a role in participants' answers, especially as they reflected on MdM and their experience with it. This might have been portrayed by families over reporting positive feedback as a result of an assessment session. It can also be seen in families reflecting on their own views of mental health services, as all perceptions were positive or neutral, hardly mirroring the highly stigmatizing views endorsed by the community as reported by participants. This also might have played a role in participant's reflection on their understanding of mental health services and their aims. In fact, a few parents and children seemed to be hesitant and worried about giving the 'wrong' answer.

It is worth mentioning that the cultural difference resulting from the interviewer being Lebanese could have also played a role, at least in part, in how participants expressed themselves. As an example, a few participants expressed believing that the interviewer would not understand what they are talking about, has never experienced similar events, or would not believe them. This was especially pertinent in reflecting on their severe financial struggles.

Furthermore, having the interviews over the phone made it difficult to control the setting in which participants are in. This was especially relevant as in some families, the young person would answer the questions using the same words, examples, and metaphors of the parent. This can be explained by the child possibly being next to the parents and listening to the interview before participating themselves. Although this was implicit in most cases, it was more overt in others as the parent's voice instructing the child on how to answer could be heard in the background.

In addition, although discrepancies were not captured in our themes, it is worth mentioning that for the same family, caregiver and child provided conflicting answers for some questions. Although this is expected for questions such as perceptions of mental health or understanding of the aims of treatment, discrepancies have also included concrete concepts such as who declined the offered treatment. For example, in one specific family the mother reported that the daughter refused to take part in treatment although the mother encouraged her to do so.

> Mother: “Yes she knows [that she was offered treatment] and she didn’t participate in it. She didn’t participate in it because she doesn’t want to participate. […] No, no. She doesn’t want to participate. Now I am telling you […] I encouraged her to speak. […] Zahra didn’t want to participate you know this is it.”

And on the other hand, the daughter described that she was really interested and eager to participate in treatment

> 14-year-old-daughter: “No, the refusal was from my parents. […] They made, they made their decision by themselves, I mean, they did not, they did not ask me or take my opinion […] Yes, I told them [that I was eager to go]. Yes, but that’s it. They made their decision. That’s it there will be no going [as in there is no way I can go]. […] I wanted to go, but my parents refused. […] Yes, I was eager to participate. […] Yes, I was upset.”

In fact, this pattern of describing that the parent was enthusiastic about attending mental health support but that the child refused the service, and vice versa, was expressed by more than one family.

In addition, and closely related to the decision of not engaging in treatment, it was common for parents to express interest in treatment, then decline the service offered without the child being aware that they were offered services or knowing what the reasons for declining the services were. In fact, many children and adolescents did not know what the reasons for not engaging in treatment were and were only hypothesizing as they spoke about what could have led their parents to take this decision.

Finally, it is worth noting that interviewees appeared to confuse different humanitarian organizations with limited clarity on what each organization has offered to the family. As an example, many caregivers would bring up the ‘United Nations’ using expressions such as ‘you helped us’, ‘if it weren’t for you’, even after clarifying that the interviewer had no relation to the United Nations. In addition, there was limited differentiation in what these organizations offer, as caregivers would confuse cash or food assistance with mental health support and vice versa.

Although this confusion was implicit, 2 families clearly showed hesitancy in reflecting on the reasons for not attending treatment. In one case, the mother described that she was interested in psychological support for her daughter’s situation to improve, but that she was disappointed as ‘we’ did not follow up or get back to the family. And in another family, the mother described that that she did go to treatment but was unable to find the location of the clinic. With further discussion, it became clear that the mother was referring to another service.

More closely linked to the analysis, it was very critical to keep our assumptions and beliefs in check. In fact, we found ourselves, at several instances during the analysis, categorizing certain perceptions of difficulties or services as ‘inaccurate’, or indirectly labeling different parenting strategies as ‘good’ or ‘bad’. Throughout the entire process, we reflected and revisited our terminologies, ensuring we point out and discuss any component that could be affected by our biases.

D. Bringing it all together

Although financial struggles and longer distance needed to reach the clinic were not found to be predictors of dropout in our quantitative analyses, they were clearly verbalized by participants as reasons for not attending the intake session. This could suggest the importance of using mixed-method studies in examining reasons for dropout to allow for a more in-depth understanding of any quantitative result.

In addition, most participants reported financial difficulties (paying for the cost of sessions as well as for transportation) as the main, and often only, reason for non-attendance. This is important as most studies related to mental health interventions do not include the cost of the service offered. It could be recommended that providing this information can help in a better understanding and interpretation of the dropouts in the service, if any.

The qualitative analysis in this study could also help interpret our quantitative results. Our content analysis shows limited knowledge of services and misconceptions of what these services could provide. This makes it challenging to interpret quantitative results on predictors of pretreatment dropout as it might indicate that our understanding and operationalization of ‘expressing interest in treatment’ is different, at least in part, from the families’ understanding. In other words, we are looking for reasons that prevented families from taking a mental health service that was offered to them, with the assumption that their initial interest in treatment was related to identifying a problem, perceiving a need for treatment, beliefs around the efficacy of treatment and so on. However, if families had other, non-mental-health related reasons to ask for treatment, the reasons for declining to engage in the service could also be unrelated to mental health. As an example, a father who expresses interest in treatment out of dire need for financial assistance will have different reasons and motives for not engaging in treatment as compared to another father who expresses interest as a result of identifying a difficulty that requires support.

In line with financial struggles and instability, the context around which our quantitative and qualitative components took place should be taken in consideration in drawing conclusions from our analyses and results. In fact, the daily instabilities and the focus on ensuring basic survival needs such as shelter, food, and safety proves that the families' state is changing drastically in short periods of time. In other words, a family can express interest in treatment at a certain point in time, but then have different needs and priorities when offered the service. In addition to this, and more specific to the qualitative component, the rapid changes occurring, and the intensity of the events, can make it challenging to recall, in an interview, reasons that prevented individuals from attending sessions offered to them around a year ago. For example, in discussing reasons for non-attendance one family described the difficulties of getting out of the house as a result of the pandemic. Although the start of the pandemic was after the service was declined, the recency effect of such highly emotional incidents occurring in the family's life can justify the focus on current threats and the difficulty remembering previous instances.

E. Strengths and limitations

Studies in the literature have examined predictors to dropout, and barriers to seeking treatment have been examined specifically in Lebanon (Karam et al., 2018). However, this is the first known study to examine predictors of pretreatment dropout in a humanitarian setting in the Arab world, and to use a mixed-method approach. Also, all symptom profile measures used have been piloted and validated with a sample of Syrian refugees in Lebanon (McEwen et al., 2021b), increasing their validity and reliability. Furthermore, the literature lacks clear operationalization of dropout and has poor differentiation of the stage of dropout. However, this study is limited to pretreatment dropouts, operationalized as people who did not participate in the intake session, making it clear specific.

Still, there were several limitations to our study. For the quantitative part, a larger sample size would allow for more variability in the sample and a better ability to detect effects. As BIOPATH is a longitudinal study, we had data on all measures collected at two different points in time (year 1 and year 2). Analyzing predictors of dropout at two different points in time and comparing differences between them was outside the scope of this project. So, to answer the hypotheses we had proposed, we had to simplify and to choose one of the two timeframes. The decision to choose year 2 data was linked to this data being closer in time to the qualitative interviews conducted. However, this choice led to a reduced sample size which subsequently reduces the power and the ability to detect effects as compared to a larger sample size, such as year 1 sample size. In addition, using the larger sample of BIOPATH could have allowed for examining the difference in predictors of pretreatment dropout across the different stages of dropout (pretreatment, early dropout, late dropout, completers). This would have yielded valuable insights on changes on predictors, if any, at the different stages.

In addition, using secondary data analysis limits our ability to operationalize and modify variables in a way that suits our research questions directly, leading to poor distributions, missing values and a reduced possibility of detecting the predictors' effect. Collecting data for the purpose of examining predictors of pretreatment dropout might have allowed for a better choice and operationalization of variables.

As for the qualitative part, conducting the interviews over the phone is a main limitation. Poor phone connection and background noises might decrease engagement in the interview questions leading to a less in-depth interview. Moreover, not being able to see the interviewer can make it more difficult to build a trusting relationship and answer truthfully. With children and adolescents, conducting the interviews over the phone made it difficult to manage who enters the room of the interviewee in order to ensure full privacy. Secondly, conducting the interviews amidst multiple crises taking place in the country is also a limitation of our study. This context made it difficult to schedule appointments, increasing to possibility of interviewees rescheduling or not answering the phone. Also, the instability and unpredictability that the families were in, as a result of the country's state, can affect their answers, especially as they were trying to reflect on the reasons that prevented them from taking part in an intervention offered to them at a time where the context was remarkably different. In addition, and similar to any qualitative study, it is not possible to generalize the results to different context, making them specific to our sample. Finally, a larger sample size might have allowed for an added layer of understanding the predictors.

F. Implications and future directions

Our qualitative results suggest a gap between what is being offered to the refugee population by mental health workers and the needs of this population. Our content analysis can be translated into several concrete recommendation as an attempt to address this gap. First, it is important to have a clear understanding of the refugees' needs and priorities throughout the process of designing, tailoring, and providing mental health interventions to this population. This could be achieved by integrating psychotherapeutic services with social work. Addressing other pressing needs the family has in parallel with mental health interventions can lead to better engagement and responsiveness to the interventions. More practically, compensating for transportation costs and any additional cost needed to be part of the services can be a major step towards preventing dropout. On the other hand, our findings suggest that providing services inside the camps, whenever possible, can be a solution to several barriers of treatment (financial barriers, transportation, safety, distance, shame, and stigma). In addition, it is crucial to provide psychoeducation before and during services. This not only validates the experiences of the individuals but can also help in addressing misconceptions of mental health difficulties and inaccurate expectations of mental health services. More specifically, stigma and shame around enuresis could be targeted through psychoeducation, awareness sessions, groups sessions, and lectures, eventually working toward desensitization around the topic. Furthermore, adopting community-based training models and participatory approached of interventions can help in having the community as a support system rather than a source of stigma.

From a research perspective, and in line with our findings, future studies should examine dropout predictors with a clear differentiation of the stage of dropout, and with a comparison of the different stages, if possible. Also, as our qualitative findings suggest, there is a lack of understanding of services offered which is linked to poor expectation and perceived need. This is line with a cross-national study showing mental health illiteracy as the most common barrier to dropout (Andrade, et al., 2014). To translate this into research, it would be helpful to measure and assess understanding and expectations of offered services in studies looking at treatment dropout. This is especially important for studies relying on quantitative measures solely. Finally, more mixed-method studies are needed about dropout in general and in the Arab world and in humanitarian setting specifically in order to address the current gap in the literature.

CHAPTER VI

CONCLUSION

This study implemented a mixed method approach and examined predictors of pretreatment dropout in a sample of Syrian refugee adolescents residing in Lebanon. The results of our study showed that only levels of PTSD predicted treatment attendance; higher levels of PTSD were associated with an increased likelihood to attend the intake session. In addition, our thematic analysis revealed 4 themes and 12 subthemes as reasons for non-attendance. The most common barrier was related to practical and logistical challenges, namely financial and transportation concerns. Stigma and shame endorsed by the community was also a common concern for parents and adolescents, however, our analyses show that most families find a way around this concern as it did not directly translate into a barrier. Although less common, perceptions of mental health difficulties and of mental health services, including limited knowledge of services, as well as concerns about confidentiality and the level of understanding of the therapist have all played a role in non-attendance. Our results show that concrete steps should be taken in order to minimize the gap between the services offered to the refugee population and their needs. When possible, compensating for transportation costs or providing sessions inside the camp can help solve many of the reasons of dropout. In addition, implementing community-based training models and providing extensive psychoeducation about the service offered can help tackle stigma, limited knowledge of services, and inaccurate perceptions of mental health difficulties. Finally, this study lays the ground for future research that examines pretreatment dropout in humanitarian settings in general, and in the Arab world in specific.

APPENDIX A

DEMOGRAPHIC CHARACTERISTICS ABOUT THE CHILD/ADOLESCENT

	Demographic data *CHILD REPORT*					
	Instructions: First of all I'm going to ask you some questions about your family background and about your health. Remember that anything you tell me will be kept secret – we won't tell anyone else, including your family, about the answers you give me.					
cDem1	Child gender	Male	Female			
cDem2	Age at testing, years					
cDem3	What is your nationality?	Syrian	Lebanese	Palestinian	Iraqi	Other
cDem5	Are you married?	Yes	No	Engaged		

APPENDIX B

DEMOGRAPHIC CHARACTERISTICS ABOUT THE CAREGIVER(S)

	Demographic data *PARENT REPORT*			
	Instructions: First of all I'm going to ask you some questions about your family background and about the health of you and your child. Remember that anything you tell me will be kept secret – we won't tell anyone else about the answers that you give me.			
pDem1	Caregiver gender	Male	Female	
pDem2	What is your relationship to the child taking part in the study? [check that they are the primary caregiver]	- Mother - Father - Stepmother - Stepfather - Aunt - Uncle - Cousin - Grandmother - Grandfather - Brother - Sister - Friend of the family - Neighbour - Other (specify):		

pDem3	Parent's age at testing					
pDem4	What is your nationality?	Syrian	Lebanese	Palestinian	Iraqi	Other
pDem7A	From which region/village/city in Syria are you originally from?					
pDem7B	Which region/village/city in Syria were you living in before moving to Lebanon?					
pDem10	How many children do you have?					
pDem10A	What position in your family is the child that you are answering questions about?	1 2 3 4 5 6 7 8 9 10 More than 10, specify:				
pDem13	Do you benefit from cash/voucher assistance (non-food, any programme)?	Yes	No			

pDem13 A	If yes, how much support do you get (sum value received in the last month, total of all programmes in USD or LBP)?	If yes, how much support do you get (sum value received in the last month, total of all programmes in USD or LBP)? $0-15 / LBP 0-23,000 $16-30 / LBP 24,000-46,000 $31-50 / LBP 47,000-76,000 $51-100 / LBP 77,000-151,000 $101-150 / LBP 152,000-227,000 >$151 / >LBP 228,000				
pDem14	Do you benefit from food assistance (any programme)?	Yes	No			
pDem14 A	If yes, how much support do you get (sum value received in the last month, total of all programmes in USD or LBP)?	If yes, how much support do you get (sum value received in the last month, total of all programmes in USD or LBP)? $0-15 / LBP 0-23,000 $16-30 / LBP 24,000-46,000 $31-50 / LBP 47,000-76,000 $51-100 / LBP 77,000-151,000 $101-150 / LBP 152,000-227,000 >$151 / >LBP 228,000				
pDem15	Do you have a job? (Remember, we won't share this information with anyone)	No	Yes			
pDem15 A	If yes, is your job:	Full time	Part time	Occasional		

pDem15B	How would you describe the type of job you have?	Wholesale and retail trade	Other services (e.g., hotel, restaurant, transport, personal services such as cleaning, hair care, cooking and child care)	Agriculture	Construction	Manufacturing	Begging	Other (please specify)
pDem27	Can you and/or other adults in your household read and write? For example, read newspapers and write a letter [Answer about the person with the highest literacy in the household]	Not at all	A little	More or less	Mostly	Absolutely yes		
pDem17A	When you lived in Syria, and before the war, what was your job (or your husband/wife's job, if they earned more)?							
pDem17	How would you categorise this particular job between the following options?	Managerial or professional (e.g., senior manager or official, doctor,	Supervisor, clerical or skilled manual worker (e.g., office supervisor or clerk, bank teller,	Semi-unskilled (e.g., cleaner, agricultural labourer, construction	Never worked/ long-term unemployed			

		lawyer, scientist, teacher)	construction or plant supervisor or operator, technician, childcare worker, skilled agricultural worker, carpenter, blacksmith, stonemason, driver, baker)	labourer, shelf-filler, porter)		

APPENDIX C

THE CENTER FOR EPIDEMIOLOGICAL STUDIES DEPRESSION SCALE FOR CHILDREN (CES-DC) – SHORTENED VERSION

	Depression (CES-DC, 10 items) *CHILD REPORT*	0 Not At All	1 A Little	2 Some	3 A Lot
	Instructions: I'm going to read you a list of the ways you might have felt or acted. Please tell me how much you have felt this way during the past month. DURING THE PAST MONTH				
cDep1	I was bothered by things that usually don't bother me.				
cDep2	I wasn't able to feel happy, even when my family or friends tried to help me feel better.				
cDep3	I felt like I couldn't pay attention to what I was doing (e.g., homework, playing, watching TV, doing chores).				
cDep4	I felt down and unhappy.				
cDep5	I felt like I was too tired to do things.				
cDep6	I was happy.				
cDep7	I felt lonely, like I didn't have any friends.				
cDep8	I felt like crying.				

cDep9	I felt sad.				
cDep10	It was hard to get started doing things.				

APPENDIX D

THE SCREEN FOR CHILD ANXIETY RELATED EMOTIONAL DISORDERS (SCARED-C) SCALE – SHORTENED VERSION

	Anxiety (SCARED, 15 items) *CHILD REPORT*	0 Not True or Hardly Ever True	1 Somewhat True or Sometimes True	2 Very True or Often True	
	Instructions: I'm going to read you a list of sentences that describe how people feel. Listen to each phrase and decide if it is "Not True or Hardly Ever True" or "Somewhat True or Sometimes True" or "Very True or Often True" for you. Then, for each sentence, tell me which response seems to describe you for the last month.				
cAnx1	I get scared if I sleep away from home.				SP
cAnx2	When I get frightened, I feel like passing out.				PN
cAnx3	I follow my mother or father wherever they go.				SP
cAnx4	I worry about things working out for me.				GD
cAnx5	I am a worrier.				GD
cAnx6	I get really frightened for no reason at all.				PN
cAnx7	I am afraid to be alone in the house.				SP
cAnx8	When I get frightened, I feel like I am choking.				PN
cAnx9	I feel shy with people I don't know well.				SC
cAnx10	I worry about what is going to happen in the future.				GD
cAnx11	When I get frightened, I feel like throwing up.				PN
cAnx12	I worry about how well I do things.				GD

cAnx13	When I get frightened, I feel dizzy.				PN
cAnx14	I feel nervous when I am with other children or adults and I have to do something while they watch me (for example: read aloud, speak, play a game, play a sport.)				SC
cAnx15	I feel nervous when I am going to parties, dances, or any place where there will be people that I don't know well.				SC

Key: PN=Panic disorder or Significant Somatic Symptoms; GD=Generalised Anxiety Disorder; SP=Separation Anxiety; SC=Social Anxiety

APPENDIX E

CHILD PTSD SYMPTOM SCALE (CPSS) (WITH SLEEPING PROBLEMS)

	PTSD (CPSS & TSC-40, 18 items) *CHILD REPORT*		
	Instructions: We’ve just talked about things that happened to you that might have been very scary, dangerous, or violent. [INTERVIEWER INSTRUCTION: recap events child has mentioned during the interview from questions about child abuse, witnessing violence at home, bullying, and war events.]		
cPTSDa	Are there any painful, distressing, or sad events that have happened to you and that still bother you today? It might be something that we already talked about, or something else. It could be a single event (for example, a car crash) or many similar events (for example, lots of stressful events during the war).	Yes	No
cPTSDb	What is the most distressing event that has happened to you and that still bothers you today?	- Event 1 - Event 2 - Event 3 - Event 4 - Event 5 [For each event:] Did it happen: - In the last month? - Over a month ago, but in Lebanon? - In Syria, after the war started? - In Syria, before the war started?	
	Instructions: I’m going to read you a list of problems that kids sometimes have after experiencing an upsetting event. Listen to each one carefully and choose the option that best describes how often that problem has bothered you IN THE LAST MONTH. Thinking about any upsetting events that have happened to you, how often has this problem bothered you in the last month?		

		0 Not at all or only at one time	1 Once in a while	2 Half the time	3 Almost always
cPTSD1	Having upsetting thoughts or images about the event that came into your head when you didn’t want them to				
cPTSD2	Having bad dreams or nightmares				
cPTSD3	Acting or feeling as if the event was happening again (hearing something or seeing a picture about it and feeling as if I am there again)				
cPTSD4	Feeling upset when you think about it or hear about the event (for example, feeling scared, angry, sad, guilty, etc)				
cPTSD5	Having feelings in your body when you think about or hear about the event (for example, breaking out into a sweat, heart beating fast)				
cPTSD6	Trying not to think about, talk about, or have feelings about the event				
cPTSD7	Trying to avoid activities, people, or places that remind you of the traumatic event				
cPTSD8	Not being able to remember an important part of the upsetting event				
cPTSD9	Having much less interest or doing things you used to do				
cPTSD10	Not feeling close to people around you				
cPTSD11	Not being able to have strong feelings (for example, being unable to cry or unable to feel happy)				

cPTSD12	Feeling as if your future plans or hopes will not come true (for example, you will not have a job or getting married or having kids)				
cPTSD13	Having trouble falling or staying asleep (excluding times when you were disturbed by other people or noise)				
cPTSD14	Feeling irritable or having fits of anger				
cPTSD15	Having trouble concentrating (for example, losing track of a story on the television, forgetting what you read, not paying attention in class)				
cPTSD16	Being overly careful (for example, checking to see who is around you and what is around you)				
cPTSD17	Being jumpy or easily startled (for example, when someone walks up behind you)				
cPTSD18	Not feeling rested in the morning				

APPENDIX F

STRENGTHS AND DIFFICULTIES QUESTIONNAIRE (SDQ)

	Externalizing behaviour (SDQ – NB using SDQ in entirety, ***10 externalising items***, 15 other items) *PARENT REPORT*	0 Not True	1 Somewhat True	2 Certainly True
	Instructions: I'm going to read you a list of ways that your son/daughter might have felt or acted. I want you to think about whether each sentence is 'Not true' or 'Somewhat True' or 'Certainly True' of your son/daughter. **SDQ Instructions:** For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.			
pSDQ1	Considerate of other people's feelings			
pSDQ2	***Restless, overactive, cannot stay still for long***			
pSDQ3	Often complains of headaches, stomach-aches or sickness			
pSDQ4	Shares readily with other children (treats, toys, pencils etc.)			
pSDQ5	***Often has temper tantrums or hot tempers***			
pSDQ6	Rather solitary, tends to play alone			
pSDQ7	***Generally obedient, usually does what adults request [R]***			
pSDQ8	Many worries, often seems worried			
pSDQ9	Helpful if someone is hurt, upset or feeling ill			
pSDQ10	***Constantly fidgeting or squirming***			
pSDQ11	Has at least one good friend			
pSDQ12	***Often fights with other children or bullies them***			
pSDQ13	Often unhappy, down-hearted or tearful			
pSDQ14	Generally liked by other children			
pSDQ15	***Easily distracted, concentration wanders***			

pSDQ16	Nervous or clingy in new situations, easily loses confidence			
pSDQ17	Kind to younger children			
pSDQ18	***Often lies or cheats***			
pSDQ19	Picked on or bullied by other children			
pSDQ20	Often volunteers to help others (parents, teachers, other children)			
pSDQ21	***Thinks things out before acting [R]***			
pSDQ22	***Steals from home, school or elsewhere***			
pSDQ23	Gets on better with adults than with other children			
pSDQ24	Many fears, easily scared			
pSDQ25	***Sees tasks through to the end, good attention span [R]***			

	Externalizing behaviour (additional DSM-5 items, 12 items) *PARENT REPORT*	0 Not True	1 Somewhat True	2 Certainly True
pExt1	Often stays out at night despite parental prohibitions			
pExt2	Runs away from home overnight (has happened at least twice)			
pExt3	Often truants from school			
pExt4	Uses weapons that can cause serious physical harm to others (e.g., a bat, bricks or stones, broken bottle, knife)			
pExt5	Is physically cruel to people			
pExt6	Destroys things belonging to other people			
pExt7	Often irritable, easily annoyed, or angry			
pExt8	Argues a lot with parents or other adults			
pExt9	Often deliberately annoys others (including people other than siblings)			
pExt10	Often blames others for his/her mistakes or misbehaviour (including people other than siblings)			
pExt11	Often spiteful or vindictive to people other than siblings			
pExt12	Is physically cruel to animals			

APPENDIX G

THE WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE FOR CHILDREN (WHODAS) – CHILD VERSION

	Disability (Adapted WHO DAS, 25 items) *CHILD REPORT*	0	1	2	3	4
	Instructions: These questions ask about problems you may have due to health conditions. Health conditions include diseases, illnesses, or other health problems that may be short- or long-lasting injuries, mental or emotional problems, or problems with alcohol or drugs. Think back over the last month and answer these questions, thinking about how much difficulty you have had doing the following activities. For each question, please give only one response.					
cWHODASh 1	How do you rate your health overall in the past month?	Very good	Good	Moderate	Bad	Very bad
cWHODASd 4.1	In the last month, how much difficulty did you have in getting along with people you do not know well?	No difficulty	A little difficulty	Moderate difficulty	Severe difficulty	Extreme difficulty OR Have not been able to do it
cWHODASd 4.2	In the last month, how much difficulty did you have in keeping a friendship?					
cWHODASd 4.3	In the last month, how much difficulty did you have in getting along with family members?					
cWHODASd 4.4	In the last month, how much difficulty did you have in making new friends?					

cWHODASd 4.5	In the last month, how much difficulty did you have in getting along with your teachers or adults who aren't in your family?					
cWHODASd 5.1	In the last month, how much difficulty did you have in doing chores or other things you are expected to do at home to help out?					
cWHODASd 5.2	In the last month, how much difficulty did you have in finishing chores or home activities that you are supposed to do?					
cWHODASd 5.3	In the last month, how much difficulty did you have in doing chores or home activities well?					
cWHODASd 5.4	In the last month, how much difficulty did you have in doing chores quickly if you have to?					
cWHODASd school	Do you go to school?	No (If no, skip to 6.1)	Yes			
cWHODASd 5.5	In the last month, how much difficulty did you have in doing your regular school assignments?	No difficulty	A little difficulty	Moderate difficulty	Severe difficulty	Extreme difficulty OR Have not been able to do it
cWHODASd 5.6	In the last month, how much difficulty did you have in studying for important school tests?					

cWHO DASd 5.7	In the last month, how much difficulty did you have in completing all of the school assignments and activities that you needed to do?					
cWHO DASd 5.8	In the last month, how much difficulty did you have in completing school work on time?					
cWHO DASd 5.9	In the last month, how much difficulty did you have in following rules or fitting in with others at school?					
cWHO DASd 6.1	In the last month, how much difficulty did you have in joining in on community activities? (clubs, prayer groups, and youth activities, etc.)					
cWHO DASd 6.3	In the last month, how much time do your parents or other family members spend on your health condition problems you may have?	Never	A little	Some of the time	A lot of the time	Always
cWHO DASd 6.4	In the last month, how much has your health condition upset you?					
cWHO DASh 2	Overall, how much did these difficulties interfere with your life?					
cWHO DASh 3	Overall, in the last month, how many days were these difficulties present?	[enter number]				

cWHODASh 4	In the last month, for how many days were you totally unable to carry out your usual activities or school work because of any health condition?	[enter number]				
cWHODASh 5	In the past month, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or school work because of any health condition?	[enter number]				
	[If child is in school]					
cWHODASh 6	In the last month, how many days were you absent from school?	[enter number]	N/A - did not attend school (holidays / school closed, etc)			
cWHODASh 7	In the past month, how many days were you late for school?	[enter number]	N/A - did not attend school (holidays / school closed, etc)			

APPENDIX H

INTERVIEW WITH CAREGIVER

Prior to interview

Check you have the necessary background information:

- Date of BIOPATH assessments
- Description of difficulties reported at the time
- Date of phone screening
- Who spoke to them
- Who in the family reported that they were interested in services
- Who the caregivers are and if this has changed (who took part in the BIOPATH study / who took the call about services / who is taking part in this interview)
- To what extent is the child/adolescent aware that they were offered treatment that was ultimately declined
- Who was involved in the decision of declining treatment (caregiver / child / both)
- Any other salient information about the phone screening

Interview with parent(s)/caregiver(s)

Introduction: Before we start, I just want to tell you who I am and what we're going to do.

- My name is XXX and I'm from XXX.
- Earlier this year/last year [insert approximate date], you participated in a study called BIOPATH [insert necessary details to make sure they remember]. At that time, you/your spouse/your child [check who requested services] told the

interviewer that XXX [child's name] had some difficulties with their feelings/behavior [mention specific reasons and difficulties given at the time]. Then a counselor from Médecins du Monde talked to you on the phone and you/your spouse told them that you were interested in getting help from them [check the caregiver understands it's the phone screening you're talking about].

- Because they had a big number of families who told them they want help from them but who then didn't attend the service, we want to try to better understand the reasons for this. So I want to find out more about what motivated you to ask for help and what prevented you from attending the assessment and therapy sessions.
- I am so happy that you've agreed to speak to me today because it will really help us understand better why families who said they needed help didn't go to get the help; and when we understand this, we can better help other families and children in the future.
- I'm not part of the counselling team, but a different team who wants to learn more about the reasons that prevented families from getting the help they wanted.
- I won't tell XXX [name of the counsellor from phone screening] or other people who work at Médecins du Monde anything about what you say. So it's ok to tell me anything that you didn't like or that you feel affected your decision on getting help from them. [Check caregiver's understanding of confidentiality and if they have questions about the interview, confidentiality, etc.] Nothing that you say will affect your access to the service, or any services, available to you.

[make sure it is clear that what they say will not be used against them in any way, or cut them off from services].

Interview:

[*If both parents / more than one caregiver is present, try to find out what each thought and if their opinions differed. Highlight that you really want to hear from both of them and that they might have different opinions. Also highlight that we want to understand people's perceptions, and even if two people disagree, we still want to hear from both of them (if necessary, normalize disagreements / different opinions and try to ensure that both are contributing opinions during the interview)*].

1. Introduction
    1.1 In the BIOPATH study XXX [person(s) who reported the difficulties] reported that XXX [child's name] has been experiencing [mention specific feelings and behaviors]. How has XXX [child's name] been since you took part in that study?
    1.2 What has been going on in your family since you took part in that study?
    1.3 Can you tell me what is happening with XXX [child's name] difficulties [mention specific difficulties] now?

Responses to questions 1.1-1.3 should then inform the way in which questions are asked in the rest of the interview (i.e. if they are seen as past/present, impairing or not etc).

2. General perceptions of mental health

- 2.1 Why do you think XXX [child’s name] is having these difficulties (What do you think are the causes)?
- 2.2 What do other people in your family or community think is the cause of these difficulties?
    - 2.2.1 What types of problems or difficulties do you often see in your community?
    - 2.2.2 What do families usually do to deal with their children’s difficulties?
- 2.3 How do you manage XXX [child’s name] difficulties? [If both caregivers are present, make sure to ask this question to both of them, separately]. *Prompt if needed: ‘People have different ways of dealing with problems like [mention the specific problem]. Sometimes they keep the child home, sometimes they get angry and frustrated, sometimes they pray, and sometimes they seek help. In what ways do you and your family cope and manage XXX’s* [child’s name] difficulties?*’*
- 2.4 [If only one caregiver is present] How does your spouse/other caregivers deal with *XXX’s* [child’s name] difficulties?
- 2.5 Is there anything going on with XXX [child’s name] that makes XXX [child’s name]’s difficulties better or worse?

3. <u>Factors leading to request for services</u>
    - 3.1 What do you think about mental health services and therapy / counselling [define and ensure understanding] generally?
    - 3.2 What do you think is offered in these services?
        - 3.2.1. What do you think is the purpose of these services?

Prompts: explore overall and specific perceptions of mental health service provisions, with a focus on psychological talking therapy; explore any misconceptions about what mental health services / therapy entails.

3.3 When Médecins du Monde first contacted you, why did you ask for the services offered?

  - *3.3.1* What did you hope or expect might be offered?
  - 3.3.2 In what ways did you think Médecins du Monde's services could help/could have helped XXX*'s* [child's name]?

3.4 Do you know any family with a child who is getting mental health treatment?

  - 3.4.1 [If no] Why do you think children with difficulties don't seek treatment?
  - 3.4.2 [If yes] How did your community react to [the child mentioned] seeing a therapist?

Prompts if needed: We have heard from some other participants that people in their community judged their children when they had mental health services. Sometimes they say words such as crazy or weak or dangerous about the person seeking help and sometimes, they distance themselves from them. Other participants, though, have said that people in their community were very happy when their child took part in mental health services, because their community wanted the child to feel better. And other people didn't have a negative or positive opinion, but they were worried about things such as the future being affected, or they were worried about people thinking that there is a problem with *the parents. What types of reactions did your community have to XXX [the child mentioned] seeing a therapist?*

3.4.3 [If yes] What types of reactions/opinions did you have about [the child mentioned] seeking therapy?

4. <u>Factors that prevented taking up or continuing the intervention</u>

4.1 Why did XXX [child's name] not end up attending the assessment/enrolling in therapy?

[If necessary, remind them that it is okay to have negative feedback about any aspect of the service and that their answers will help us better help families and children in the future].

Prompts: Sometimes families have difficulties getting to appointments because they have so many other things going on at home, sometimes they worry about what others will think of them and their child, sometimes they do not think the service or therapy will help. Sometimes people think the difficulties will go away on their own, or that they have already gone away. What are the reasons that XXX [child's name] did not enroll in therapy?

4.1.1 What concerns did you have about the therapist not being able to understand or relate to XXX [child's name] or his/her difficulties [name specific difficulties]?

Prompts: Probe for cultural differences as a barrier to seek treatment with a Lebanese therapist, concerns of being a minority group, and not being understood, or valued.

4.1.2 What concerns did you have about the privacy of what XXX [child's name] would disclose in treatment if he/she attended the assessment/therapy?

4.1.3 To what extent were you concerned about how other families would perceive XXX [child's name] attending a mental health service/therapy?

4.1.4 Can you tell me about any practical problem that prevented XXX [child's name] from attending the service?

Prompts: Probe about having other children at home, finding it difficult to find time to go to therapy, having problems with transportations, clinic is far, financial problems, etc.

4.1.5 Is there anything else that prevented XXX [child's name] from attending the assessment/therapy that I didn't ask you about?

4.2 [Assess for pretreatment assessment alliance, both for parent and parent's perception of the child's alliance] If you try to remember when someone from Médecins du Monde called you on the phone to ask you a few questions and tell you about their services [remind them that they can be honest and nothing they say will be directly feedback to the service, nor will it affect their treatment by the service]:

4.2.1 To what extent did you feel that you and your child were comfortable talking to that person?

4.2.2 To what extent did you feel that you were able to trust them and answer honestly (talk about private problems)?

4.2.3 To what extent did you feel that they were understanding you?

        - 4.2.4 To what extent did you feel that Médecins du Monde's services in general, and the phone assessment in particular, service was organized, reliable, and well structured?
    - 4.3 How did this/these issue(s) [name any issues from 4.2] affect your decision about XXX [child's name] attending the assessment/enrolling in therapy?
    - 4.4 Have you discussed XXX [child's name] enrolling in therapy with anyone else? (e.g. other members of the family, anyone in the community)
        - 4.4.1 [If yes] Did they help you or did they have a role in making the decision? How?
        - 4.4.2 [If no] why?

5. <u>Suggestions on how to improve the accessibility of the intervention</u>
    - 5.1 Although many families said that their child needed mental health services, very few families actually used these services when we offered them. Why do you think that families may not have come to therapy?
    - 5.2 What do you think would encourage other families to attend therapy?
    - 5.3 Can you think of anything that, if done differently, would have made it easier for XXX [child's name] to attend Médecins du Monde's service? *Prompts: Ask this question specifically using all examples from section 4, such as practical barriers, perceptions of the service, organization etc.*
    - 5.4 What might have encouraged XXX [child's name] to attend the assessment/therapy?
    - 5.5 What do you think we can change to make it easier or encourage other families and children to attend and benefit from these services?
    - 5.6 Is there anything that you would like to add that we did not already discuss?

6. Before we speak with XXX [child's name], could you tell us to what extent she/he is aware of her/his difficulties and whether she/he knows she/he was referred for mental health support? This will help us to make sure we ask the right kind of questions.
    6.1. Did you discuss with XXX [child's name] the offer of treatment? Could you tell me more about this?
    6.2. Does XXX [child's name] know that they were offered treatment that they didn't get?
    6.3. Was it only your decision not to attend the session, or XXX [child's name]'s decision, or did you discuss this together?

Child and adolescent interviews should then be tailored to their age and level of prior knowledge.

Debrief:

- Thank you very much for talking to me today. It has really helped me understand some of the problems that make it difficult for families and children to benefit from services they want.
- Like I said at the beginning, everything you said in the interview is private, no one will know about it.
- We will only use the things you told us to try to better help other families and children in the future.
- So that other people learn about the problems that might prevent someone from attending therapy, we will write reports for other people to read. In these reports, we will never mention your name, your child's name, or your family's name.

We might include some of the words you or XXX [child's name] said, but we won't include your names, so no one will know it was you. [Check for understanding about confidentiality.]

- Do you have any questions about this interview, or about what we do with the information you gave us?
- If any question or concern comes to your mind later on and you would like to talk to someone, you can contact Dr. Alaa Hijazi at the American University of Beirut, her contact details are written here [show consent form].
- If XXX [child's name] or anyone else wants mental health services in the future or, has some questions about difficulties they are having and needs help, you can contact Médecins du Monde and they will be able to help you. You can call XXX [name of person] at XXX [phone number].

APPENDIX I

INTERVIEW WITH ADOLESCENTS

Interview with adolescent (13-17 years old)

Introduction**:** Before we start, I just want to tell you who I am and what we're going to do.

- My name is XXX and I'm from XXX.
- Earlier this year [insert approximate date], you participated in a study called BIOPATH [insert necessary details to make sure they remember]. At that time, you/your parents [check who requested services] told the interviewer that you had some difficulties with your feelings/behavior [mention specific reasons and difficulties given at the time]. Then a counselor from Médecins du Monde talked to your parents through the phone and your parents told them that you were interested in getting help from them.
- Because they had a big number of families who told them they want help from them but who then didn't attend the interview, we want to try to better understand the reasons for this. So I want to find out more about what led you to ask for their help at first, and why you didn't come to their service.
- I am so happy that you've agreed to speak to me today because it will really help us understand better what didn't let families get the help they need; and when we understand this, we can better help other families and adolescents in the future.
- I'm not part of the counselling team, but a different team who wants to learn more about the reasons that prevented families from getting the help they wanted.

- I won’t tell anyone who contacted you/your parents, or other people who work at Médecins du Monde anything about what you say. So it’s ok to tell me anything that you didn’t like or that you feel affected your decision on getting help from them. [Check adolescent’s understanding of confidentiality and if they have questions about the interview, confidentiality, etc.]

Interview:

1. Introduction

    1.1 In the BIOPATH study you/your parent(s) [check who requested services] reported that you have been experiencing [mention specific feelings and behaviors].

        1.1.1 What do you remember about this request? [explore details of who/what was requested/how they felt about it at the time]

    1.2 How have you been since you took part in that study?

    1.3 What has been going on in your family since you took part in that study? *Prompts: ‘Would you say that things with you and your family are still the same as compared to when you told* Médecins du Monde *you wanted their help? Would you say things have changed? If they did change, how?’*

    1.4 Can you tell me a bit about how these difficulties [mention specific difficulties] are now?

    1.5 And how they affect you?

Responses to questions 1.1-1.5 should then inform the way in which questions are asked in the rest of the interview (i.e. if they are seen as past/present, impairing or not etc).

2. <u>General perceptions of mental health</u>

   2.1. Why do you think you're having these difficulties? (What do you think are the causes of your difficulties?)

   Prompts: Imagine that a friend asked you about your [mention specific feelings and behaviors] and that this friend doesn't understand these [mention specific feelings and behaviors]. How would you explain to him/her your difficulties and where they come from, to help him/her better understand?

   2.2. What do other people around you such as family members, neighbors, and friends think about your difficulties *[mention specific feelings and behaviors]*?

   2.3. What types of difficulties do your friends and neighbours have?

      2.3.1. What do families that you know usually do when their children are having difficulties?

      Prompts: Maybe if you try to think about a specific family or person in mind, it would be easier to answer this question

   2.4. How do you deal with your difficulties?

   Prompts: People have different ways of dealing with problems like [mention the specific problem]. Sometimes they distance themselves from others and they avoid talking to others, sometimes they get angry and frustrated, sometimes they pray, sometimes they smoke or drink, or hurt themselves or others. Sometimes they do things that they like such as a hobby, and sometimes they talk to a friend or they ask for help. What do you do?

   2.5. How does your family (mum/dad/siblings/other caregivers) deal with your difficulties?

2.6. Is there anything going on with you that makes your difficulties better or worse?

3. Factors leading to request for services

3.1. What do you think about mental health services and talking therapy/counselling [define and ensure understanding] generally?

3.2. What do you think is offered in these services?

3.2.1. What do you think is the purpose of these services?

Prompts: explore overall and specific perceptions of mental health service provisions, with a focus on psychological talking therapy; explore any misconceptions about what mental health services / therapy entails. If a definition is needed: Mental health services are there to help people who are experiencing difficult feelings or behaviors, and usually involve talking with a psychologist or counsellor, or sometimes with a psychiatrist, who may also prescribe medication.

3.3. When Médecins du Monde first contacted your parents, why did you/your parent(s) [check who requested services] ask for their services?

3.3.1. What did you hope or expect they would offer?

3.3.2. How/what ways did you think Médecins du Monde's services could help/could have helped you?

3.4. Do you know any family with a child who is getting mental health treatment?

3.4.1 [If no] Why do you think children with difficulties don't seek treatment?

3.4.2 [If yes] How did your community (friends and family) react to [the child mentioned] seeing a therapist?

Prompts if needed: We have heard from some other participants that people in their community judged their children when they had mental health services. Sometimes they say words such as crazy or weak or dangerous about the person seeking help and sometimes, they distance themselves from them. Other participants, though, have said that people in their community were very happy when their child took part in mental health services, because their community wanted the child to feel better. And other people didn't have a negative or positive opinion, but they were worried about things such as the future being affected, or they were worried about people thinking that there is a problem with the parents. What types of reactions did your community have to [child] seeing a therapist?"

3.4.3. [If yes] What types of reactions/opinions did you have about [the child mentioned] seeking therapy?

4. <u>Factors that prevented taking up or continuing the intervention to request for services</u>

4.1. Why did you not end up attending the assessment/enrolling in treatment? [If necessary, remind the child that it is okay to have negative feedback about any aspect of the service and that their answers will help us better help families and children in the future].

Prompts: Sometimes young people or parents have difficulties getting to appointments because they have so many other things going on at home, sometimes people worry about what others will think of them, sometimes they do not think the service or therapy will help. Sometimes people think the *difficulties will go away on their own, or that they have already gone away. In your case, what are the reasons that you did not enroll in therapy?*

4.1.1. What concerns did you have about the therapist not being able to understand you or relate to your difficulties [name specific difficulties]?

Prompts: Probe for cultural differences as a barrier to seek treatment with a Lebanese therapist, concerns of being a minority group, and not being understood, or valued.

4.1.2. What concerns did you have about the privacy of what you say in treatment if you have attended the assessment/therapy?

4.1.3. To what extent were you concerned about what other families or adolescents would think or say about you attending a mental health service/therapy?

4.1.4. Can you tell me about any practical problems that prevented you from attending the service?

Prompts: Probe about having younger siblings at home, finding it difficult to find time to go to therapy, having problems with transportations, clinic is far, financial problems, etc.

4.1.5. Is there anything else that prevented you from attending the assessment/therapy that I didn't ask you about?

4.2. Have you talked to anyone about the possibility of you attending therapy? (e.g. siblings, friends)

4.2.1. [If yes] Did they help you or did they have a role in making the decision? How?

4.2.2. [If no] why?

5. Suggestions on how to improve the accessibility of the intervention

5.1. Although many families and children said that they needed mental health services, very few families actually used these services when we offered them. Why do you think that families may not have come to therapy?

5.2. What do you think would encourage other families to attend therapy?

5.3. Can you think of anything that, if done differently, would have made it easier for you to attend Médecins du Monde's services?

Prompts: Ask this question specifically using all examples from section 4, such as practical barriers, perceptions of the service, organization etc.

5.4. What might have encouraged you to attend the assessment/therapy?

5.5. What do you think we can change to make it easier or encourage other families and children to attend and benefit from these services?

5.6. Is there anything that you would like to add that we did not already discuss?

Debrief:

- Thank you very much for talking to me today. It has really helped me understand more how the services we offer are perceived and why it might be difficult for some families and children to benefit from services they want.
- Like I said at the beginning, everything you said in the interview is private, no one will know about it.
- We will only use the things you told us to try to better help other families and children in the future.
- So that other people learn about the problems that might prevent someone from attending therapy, we will write reports for other people to read. In these reports,

we will never mention your name, you parents' names, or your family's name. We might include some of the words you or your parents said, but we won't include your names, so no one will know it was you. [Check for understanding about confidentiality.]

- Do you have any questions about this interview, or about what we do with the information you gave us?
- If any question or concern comes to your mind later on and you would like to talk to someone, you can contact Dr. Alaa Hijazi at the American University of Beirut, her contact details are written here [show consent form].
- If you or anyone else wants mental health services in the future or, has some questions about difficulties they are having and needs help, you can contact Médecins du Monde and they will be able to help you. You can call XXX [name of person] at XXX [phone number].

APPENDIX J

INTERVIEW WITH CHILDREN

Interview with child (8-12 years old)

Introduction**:** Before we start, I just want to tell you who I am and what we're going to do.

- My name is XXX and I'm from XXX.
- Earlier this year [insert approximate date], you participated in a study called BIOPATH [insert necessary details to make sure they remember]. At that time, you/your parents [check who requested services] told the interviewer that you had some difficulties with your feelings/behavior [mention specific reasons and difficulties given at the time]. Then a counselor from Médecins du Monde talked to your parents through the phone and your parents told them that you were interested in getting help from them.
- Because they had a big number of families who told them they want help from them but who then didn't attend the interview, we want to try to better understand the reasons for this. So I want to find out more about what led you to ask for their help at first, and why you didn't come to their service.
- I am so happy that you've agreed to speak to me today because it will really help us understand better what didn't let families get the help they need; and when we understand this, we can better help other families and children in the future.
- I'm not part of the counselling team, but a different team who wants to learn more about the reasons that prevented families from getting the help they wanted.

- I won’t tell anyone who contacted you/your parents, or other people who work at Médecins du Monde anything about what you say. So it’s ok to tell me anything that you didn’t like or that you feel affected your decision on getting help from them. [Check child’s understanding of confidentiality and if they have questions about the interview, confidentiality, etc.]

<u>Interview</u>:

1. <u>Introduction</u>
    1.1. Before I ask you a few questions about the help Médecins du Monde offers, how about we start by getting to know each other a bit? Do you like drawing? Would you be able to draw a picture of you and your family?’ [spend some time on the picture and asking non-intrusive questions and remind the child that no one will see the drawing if they don’t want them to].

    Prompts: What are the things that you and your family like doing the most? The least? What are the most difficult things facing you and your family? What are the kinds of things that have helped or could help you or your family?

    1.2. In a previous study called BIOPATH that you were part of, you/your parent(s) [check who requested services] said that you have been experiencing [mention specific feelings and behaviors].
        1.2.1. What do you remember about this request? [explore details of who/what was requested/how they felt about it at the time]
        1.2.2. How about we draw pictures of these different emotions? Would you like to draw pictures of other emotions that we didn’t mention? What does happiness look like? [spend time on the pictures and

exploring their understanding of difficult emotions and mental health/mental health services].

1.2.3. Can you tell me how have you been since you took part in that study?

1.3. What has been going on in your family and with your difficulties since you took part in that study?

Prompts if needed: 'If you think about the difficulties [mention specific difficulties] that you were experiencing, are they now still the same as they were before? Are they still bothering you? Are they less difficult or more difficult now?'

Responses to questions 1.1-1.3 should then inform the way in which questions are asked in the rest of the interview (i.e. if they are seen as past/present, impairing or not etc).

2. General perceptions of mental health

2.1. Imagine that a friend asked you about your [mention specific feelings and behaviors] and that this friend doesn't understand these [mention specific feelings and behaviors]. How would you explain to him/her your difficulties and where they come from, to help him/her better understand them?

2.2. What do other people around you such as family members, neighbors, and friends think about your difficulties?

2.2.1. What types of difficulties do your friends and neighbours have?

2.2.2. What do families that you know usually do to deal with their children's difficulties?

Prompt if needed: 'Maybe if you try to think about a specific family or person in mind, it would be easier to answer this question'

2.3. People have different ways of dealing with problems like [mention the specific problem]. Sometimes they distance themselves from others and they avoid talking about their difficulties to anyone, sometimes they get angry and frustrated, sometimes they pray, sometimes they do things that they like such as a hobby, and sometimes they talk to a friend or they ask for help. How do you usually deal with your difficulties?

2.4. How does your family deal with your difficulties (mom/dad/siblings/ other caregivers)?

2.5. Is there anything going on around you that makes it easier/harder to deal with your difficulties?

3. Factors leading to request for services

3.1. What do you think about mental health services and therapy/counselling generally?

3.2. What do you think is offered in these services?

3.2.1. What do you think is the purpose of these services?

Prompts: explore overall and specific perceptions of mental health service provisions, with a focus on psychological talking therapy; explore any misconceptions about what mental health services / therapy entails. If a definition is needed: Mental health services are there to help people who are experiencing difficult feelings or behaviors, and usually involve talking with a psychologist or counsellor, or sometimes with a psychiatrist, who may also prescribe medication.

3.3. When Médecins du Monde first contacted your parents, why did you/your parent(s) [check who requested services] ask for their services/help?

3.3.1. What did you hope or expect they would offer?

3.3.2. How do you think (or in what ways) mental health services could help/could have helped you?

3.4. Do you know any family with a child who is getting mental health treatment?

3.4.1. [If no] Why do you think children with difficulties don't seek treatment?

3.4.2. [If yes] How did your community (friends and family) react to [the child mentioned] seeing a therapist?

Prompts: We have heard different things from other participants. Some people say that people in their community have said bad things about children who went to therapy. Sometimes they say words such as crazy or weak or dangerous about the person seeking help and sometimes, they decide that they don't want to be close with them. Other people, though, have said very positive things. For example, that people in their community were very happy when their child went to therapy, because their community wanted the child to feel better and get the help he/she needs. And other people didn't have a negative or positive opinion, but they were worried about different things such as people thinking that there is a problem with the parents. What types of reactions did your community have to [child] seeing a therapist?"

3.4.3. [If yes] What types of reactions/opinions did you have about [the child mentioned] seeking help?

4. <u>Factors that prevented taking up or continuing the intervention to request for services</u>

4.1. Do you know why you didn't go to get help from Médecins du Monde?

Prompts: It's ok if you don't know, or are not sure. I am only asking these questions to see if we can figure out better ways to help children. Some children tell us they or their parents don't have time to come to the clinic, or money for the taxi, or that other people say bad things about them for going. Sometimes people just don't think that the service or therapy will help, that the difficulties will go away on their own, or that they have already gone away. What are the reasons that stopped you or your parents from coming?

4.2. Have you talked to anyone about the possibility of you getting help from Médecins du Monde? (e.g. siblings, friends)

4.2.1. [If yes] Did they change your opinion about getting help? How?

4.2.2. [If no] why?

5. <u>Suggestions on how to improve the accessibility of the intervention</u>

5.1. A lot of children wanted Médecins du Monde to help them at first. But later on, only a few came back for the help. Why do you think children and families may not have come back? [If necessary, remind the child that it is ok not to know the answer or not to be sure.]

5.2. What do you think would encourage other children like you to get help?

5.3. What do you think would have made it easier for you to get help from them?

Prompts: Ask this question specifically using all examples from section 4, such as practical barriers, perceptions of the service, organization etc.

5.4. What do you think we can change to make it easier or encourage other families and children to attend and benefit from these services?

5.5. Is there anything that you would like to add that we did not already discuss?

Debrief:

- Thank you very much for talking to me today and for drawing the picture. It has really helped me better understand how to help children experiencing difficult things.
- Like I said at the beginning, everything you said in the interview is private, no one will know about it.
- We will only use the things you told us to try to better help other families and children in the future.
- So that other people learn about the problems that might prevent someone from attending therapy, we will write reports for other people to read. In these reports, we will never mention your name, you parents' names, or your family's name. We might include some of the words you or your parents said, but we won't include your names, so no one will know it was you. [Check for understanding about confidentiality.]
- Do you have any questions about this interview, or about what we do with the information you gave us?
- If any question or concern comes to your mind later on and you would like to talk to someone, you can contact Dr. Alaa Hijazi at the American University of Beirut, her contact details are written here [show consent form].
- If you or anyone else wants mental health services in the future or, has some questions about difficulties they are having and needs help, you can contact Médecins du Monde and they will be able to help you. You can call XXX [name of person] at XXX [phone number].

APPENDIX K

CONSENT FORMS FOR PARENTS

Parents' Consent to Participate and Permission for Child to Participate in Interviews

Phase II Interviews with families who did not access mental health services:

Version 1.0 (9th September 2019)

Project Title: **Development, Piloting and Evaluation of a Phone-Delivered Psychological Intervention (t-CETA) for Syrian Refugee Children in Lebanon: Phase II**
Protocol Number: **SBS-2018-0582D**
Principal Investigator(s): **Dr. Tania Bosqui**
Address: **American University of Beirut**
Phone: **01 350-000 ext 4370**
Site where the study will be conducted: **Participant homes / Médecins du Monde clinic, Zahle, Beqaa**

Dear Parents,

This is a permission form for you and for your child/child for whom you are legal guardian to participate in a research study. It contains important information about this study and what to expect if you decide to participate and to permit your child/child for whom you are legal guardian to participate.

Your participation and your child's participation are voluntary.

Please consider the information carefully before you decide to participate or to allow your child to participate. If you decide to permit participation, you will be asked to sign this form or voice your agreement and will receive a copy of the form.

We are recruiting families who already took part in "Biological Pathways of Risk and Resilience in Syrian Refugee Children (BIOPATH)" – and who were offered, but declined, mental health services for their child – to take part in an additional study.

What is this study about?

We are inviting you and your son/daughter to participate in a research study about the key reasons for Syrian refugee children and adolescents resident in Lebanon not using mental health services that are available. Declining or dropping out of services has been shown to be linked to different factors. We want to explore these different factors in a sample of Syrian refugee children and adolescents so that we can understand why people don't use mental health services. In this part of the study we want to find out about the experiences of parents and their children who expressed an interest in treatment but later declined or dropped out.

Who is the study conducted by?

The study is conducted by a team of researchers and psychologists from several universities, including Dr. Michael Pluess, Dr. Fiona McEwen, and Dr. Kristin Hadfield from Queen Mary University of London, and Dr. Tania Bosqui from the American University of Beirut. The study is a collaboration with NGO Médecins du Monde (MdM) Lebanon.

Why have I been selected?

We are inviting families from the BIOPATH study who expressed an interest in mental health treatment for their child but then decided not to use the service offered by Médecins du Monde.

What will my child and I be asked to do?

You and your child will each be asked to take part in an interview (there will be a separate interview for you [and your child's other parent, if available] and your child). These interviews will include questions about the main reasons that led you to ask for mental health services for your child, and the reasons for deciding not to take up the service or continue with counselling.

This will take place either in your home or in a private room in the MdM clinic in Zahle.

We will audio record the interviews so that we can accurately put in written form what you and your child tell us. If you do not want us to audio record, then a second interviewer will be present and will take notes during the discussion.

Do we need to take part in the study?

Participation in this study is entirely voluntary. Refusal to participate will involve no penalty or loss of benefits or relationship with Médecins du Monde in any way. If at any time and for any reason, you would prefer not to answer any questions, please feel free to skip those questions. If at any time you would like to stop participating or wish for your child to stop participating, you are free to do so without any negative consequences. We can take a break, stop and continue at a later date, or stop altogether. You and your child will not be penalized for deciding to stop participation at any time.

Will my information be confidential?

Your individual privacy and confidentiality of the information you provide will be maintained at all times and in all published and written data analysis resulting from the study. Audio recordings will be stored on secure, password protected computers only until they have been transcribed (put in written form). Once they have been transcribed they will be deleted/destroyed. Information you give will be stored on secure, password protected computer systems and will only be available to authorized members of the study team. Anonymous data will be kept beyond the end of the study. This is to ensure that the researchers have time to analyze the data and publish the results in scientific journals.

However, please note that the Institutional Review Board monitors records and may audit them. This is to check that the study is being carried out correctly and to high standards.

If there is a serious risk of harm to your child (e.g., risk of suicide or harm by others) then we will need to disclose this information to other agencies in order to get appropriate help for your child. We will aim to do this with your knowledge and consent, if possible, unless this would delay vital treatment or services for your child.

Are there any risks or benefits to taking part?

There is no direct benefit of participation in this interview. However, information from this study will likely benefit other Syrian refugee children now or in the future by helping us better understand the factors that make it difficult for children and adolescents to access mental health services. This might inform NGO's when they are designing and planning programs that provide psychosocial support for Syrian refugees in Lebanon.

By you and your child taking part in this study, you and him/her may experience the following risks: Answering questions about your child's difficulties and experiences may cause you to feel some anxiety and sadness. However, we anticipate that any discomfort you experience will pass quickly. If you or your child's discomfort does not pass quickly, your interviewer will refer you to the appropriate services.

Will I be compensated for my participation?

You will receive 10,000 L.L at the beginning of the interview to compensate for your time and costs associated with study participation. The interview with your child will take around 45 minutes to complete and the interview with you (and your child's other parent, if available) will take around 1 hour to complete. If you and your child come to the clinic to do the interview, you will be provided with up to an additional 10,000 L.L. to cover the cost of your transportation.

What happens if there is a problem?

If you are harmed as a result of your participation in the study, you will be compensated, provided that, on the balance of probabilities, an injury was caused as a direct result of the procedures you received during the course of the study. These special compensation arrangements provided by QMUL apply where an injury is caused to you that would not have occurred if you were not in the study. This does not affect your right to pursue a claim through legal action.

Who should I talk to if I have any concerns or questions?

If you have any questions, you are free to ask them now. If you have questions, concerns or complaints about this research study later, you may contact the study Principal Investigator at the American University of Beirut:

Dr. Tania Bosqui in the American University of Beirut [English speaking]
Tel: 01-350000 ext 4370
Email: tania.bosqui@aub.edu.lb
Dr Alaa Hijazi in the American University of Beirut [Arabic speaking]
Tel: 01-350000 ext 4360/4361
Email: ah177@aub.edu.lb

If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about research or the rights of your child as a research participant, please contact the AUB Social & Behavioral Sciences Institutional Review Board (SBSIRB) at AUB: 01-350000 Ext. 5444/5445

Who has reviewed this study?

The study has been reviewed by the sponsor of this study, Queen Mary University of London, and the institutional review board at the American University of Beirut to ensure that it is conducted in an ethical and legal way.

	Yes	No
I have read (or someone has read to me) this form and I am aware that I am being asked to give permission for my minor child (or child under my guardianship) to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I will be given a copy of this form**.**	☐	☐
I understand that participation is voluntary and that I and my son/daughter are free to withdraw at any time, without giving up any legal rights or medical care.	☐	☐
I agree that I and my child/child under my guardianship can participate in this study.	☐	☐
I understand that all data we provide will be anonymous and will be kept for at least 20 years after the end of the study.	☐	☐

TO BE COMPLETED BY PARENT

I the undersigned (Name): ______________________________; Parent of (child's name): ______________________________

Date: ________________ Signature of parent: __________________________

TO BE COMPLETED BY RESEARCHER

Name of researcher taking consent: ________________________________

Date: _______________   Signature of researcher:

____

IF ORAL CONSENT IS OBTAINED, TO BE COMPLETED BY INDEPENDENT WITNESS

Name of witness to consent: ________________________________

Date: _______________   Signature of

witness:_____________________

APPENDIX L

ASSENT FORMS FOR CHILDREN: FROM 13 TO 17 YEARS OLD

Child Assent Form to Participate in Interviews (for 13-17 years)

Phase II Interviews with families who did not access mental health services:

Version 1.0 (9th September 2019)

Project Title: **Development, Piloting and Evaluation of a Phone-Delivered Psychological Intervention (t-CETA) for Syrian Refugee Children in Lebanon: Phase II**

Protocol Number: **SBS-2018-0582D**

Principal Investigator(s): **Dr. Tania Bosqui**

Address: **American University of Beirut**

Phone: **01 350-000 ext 4370**

Site where the study will be conducted: **Participant homes / Médecins du Monde clinic, Zahle, Beqaa**

- **You are being asked to be in a research study. Studies are done to find better ways to treat people.**
- **You are being asked to take part because you already took part in an earlier study (BIOPATH) and you or your parent/s have showed interest in our services but did not end up taking them up.**
- **This form will tell you about the study to help you decide whether or not you want to participate.**

- **You should ask any questions you have before making up your mind. You can think about it and discuss it with your family or friends before you decide.**
- **It is okay to say “No” if you don’t want to be in the study. If you say “Yes” you can change your mind and quit being in the study at any time without getting in trouble.**
- **If you decide you want to be in the study, an adult (usually a parent) will also need to give permission for you to be in the study.**

1. What is this study about?

This study wants to find out what makes it difficult for Syrian refugee children and adolescents who live in Lebanon to engage in mental health services that are available. In this part of the study we want to find out about the experiences of families who did not end up using our services even though they first said that they wanted to use them.

2. What will I need to do if I am in this study?

You will be asked some questions during an interview. These questions will be about some of the difficulties you might have. We also want to know about what might have stopped you from using our mental health services.

We will audio record this interview so that we can accurately put in written form what you tell us. If you do not want us to audio record, then a second interviewer will be present and take notes during the discussion.

3. How long will I be in the study?

The interview will take about 45 minutes to complete.

4. Can I stop being in the study?

You may stop being in the study at any time. You can stop the interview at any time. You won't be penalized for stopping and you will still be able to get treatment from Médecins du Monde if you wish to.

5. What bad things might happen to me if I am in the study?

Answering questions or talking about difficult things that have happened to you or how you are feeling might make you feel sad, anxious, or upset. We find that these feelings would usually go away after a little while. If these feelings don't go away soon, your interviewer will refer you to the appropriate people who will help you deal with them.

6. What good things might happen to me if I am in the study?

Taking part in the interview probably won't help you directly, though we hope that the things you tell us will help us provide treatment for other Syrian refugee children in the future.

7. Will I be given anything for being in this study?

Your family will be given 10,000 LL at the beginning of the appointment before the interview. If you and your family come to the clinic to answer the questions, we will also give your family up to 10,000 LL to cover your transportation costs.

8. What will happen with the information that I give you?

We will keep any information that you give us safely on password protected computers. Audio recordings will be stored on password protected computers only until they have been put in written form. After this, the recordings will be deleted/destroyed.

Only the researchers will look at the information you give us – they won't share it with anyone else. They won't tell anyone that you are taking part. The researchers will write reports with the results, but they won't use your name or other personal information about you.

The only time we will tell anyone else about what you have said is if you tell us that there a serious risk to your safety and we need to get help for you.

9. What happens if there is a problem?

If you are hurt as a result of being in the study, you will be compensated. These special compensation arrangements provided by QMUL apply if an injury is caused to you that would not have happened if you were not in the study. This does not affect your right to pursue a claim through legal action.

10. Who can I talk to about the study?

For questions about the study you may contact:

Dr. Tania Bosqui in the American University of Beirut [English speaking]
Tel: 01 350-000 ext 4370
Email: tb33@aub.edu.lb

Dr Alaa Hijazi in the American University of Beirut [Arabic speaking]

Tel: 01-350000 ext 4360/4361

Email: ah177@aub.edu.lb

To discuss other study-related questions with someone who is not part of the research team, you may contact the AUB Social & Behavioral Science Institution Review Board at 01-350000 Ext. 5444/5445.

	Yes	No
I have read (or someone has read to me) this form and I am aware that I am being asked to take part in a research study. I have had a chance to ask questions, my questions have been answered, and I understood the answers. I will be given a copy of this form.	☐	☐

I understand that participation is voluntary, that I can stop at any time, and that I will still be able to get medical care. ☐ ☐

I want to take part in this research study. ☐ ☐

I understand that all the information that I give will be anonymous and will be kept for at least 20 years after the end of the study. ☐ ☐

TO BE COMPLETED BY PARTICIPANT:

I the undersigned (Name): ______________________________

Date: ________________ Signature of participant:_________________________

TO BE COMPLETED BY RESEARCHER

Name of researcher taking consent: _________________________________

Date: ________________ Signature of researcher:______________________

IF ORAL CONSENT IS OBTAINED, TO BE COMPLETED BY INDEPENDENT WITNESS

Name of witness to consent: _________________________________

Date: ________________ Signature of witness:______________________

APPENDIX M

ASSENT FORMS FOR CHILDREN: FROM 8 TO 12 YEARS OLD

Child Assent Form to Participate in Interviews (for 8-12 years)

Phase II Interviews with families who did not access mental health services:

Version 1.0 (9th September 2019)

Project Title: **Development, Piloting and Evaluation of a Phone-Delivered Psychological Intervention (t-CETA) for Syrian Refugee Children in Lebanon: Phase II**
Protocol Number: **SBS-2018-0582D**
Principal Investigator(s): **Dr. Tania Bosqui**
Address: **American University of Beirut**
Phone: **01 350-000 ext 4370**
Site where the study will be conducted: **Participant homes / Médecins du Monde clinic, Zahle, Beqaa**

We want to tell you about a research study we are doing. A research study is a special way to find out about something. We are trying to find out more about a better way of offering help to Syrian children who are experiencing difficulties with their feelings or behaviour. In some cases, families and children who are offered help decide to not to take up the offer. In this study, we want to better understand what children think about our mental health service, and reasons why they might not want to come. Once we know these reasons, we might be able to better understand how to help other children with difficulties.

You are being asked to join this part of the study because you or your parents showed interest in getting help from us but did not take up the service.

If you decide that you want to be in this part of the study, this is what will happen.

1. We will ask you some questions about some of the problems you might be experiencing. We will also ask you about some of the reasons that you might be

interested in our help or some of the reasons that stopped you from coming to us for some help. This will take about 45 minutes.

2. We will make an audio recording while we're talking to you. This means recording your voice as you're talking so that we don't miss anything you said. We will listen back so that we can write down everything you said. After that we'll delete the recording (wipe the recorder clean). If you do not want us to audio record, then a second interviewer will be present and take notes during the discussion.
3. We'll do this at the clinic or your home.

Can anything bad happen to me?

We want to tell you about some things that might hurt or upset you if you are in this study. Talking about bad things that have happened to you or how you are feeling might make you feel sad or upset. Usually these feelings go away after a little while. If these feelings don't go away soon, your counsellor might arrange for you to see someone else, like a doctor, to see if you need more help.

Can anything good happen to me?

We don't know if being in this research study will help you feel better. But we hope to learn something that will help other people someday.

Do I have other choices?

You can choose not to be in this study.

Even if you decide not to be in this study, we will still take care of you and help you if you want us to.

Will anyone know I am in the study?

We won't tell anyone you took part in this study. When we are done with the study, we will write a report about what we found out. We won't use your name in the report.

<u>Will you tell anyone else about anything I've said?</u>

The only time we will tell anyone else about what you have said is if you tell us that you might get seriously hurt (at home or anywhere else). In that case the counsellor will need to get help for you.

<u>What happens if I'm worried about the study?</u>

We have told your parent / caregiver what to do if you're worried about the study or if anything goes wrong.

Before you say yes to be in this study, be sure to ask us to tell you more about anything that you don't understand.

<u>What if I do not want to do this?</u>

You don't have to be in this study. It's up to you. If you say yes now, but you change your mind later, that's okay too. All you have to do is tell us.

If you want to be in this study, please sign or print your name.

	Yes	No
I want to take part in this research study.	☐	☐

TO BE COMPLETED BY PARTICIPANT:

Child's Name:______________________________

Date: ________________ Signature of child:_________________________

TO BE COMPLETED BY RESEARCHER

Name of researcher taking consent: _________________________________

Date: ________________ Signature of researcher:______________________

IF ORAL CONSENT IS OBTAINED, TO BE COMPLETED BY INDEPENDENT WITNESS

Name of witness to consent: _________________________________

Date: ________________ Signature of witness:______________________

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