BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-032809
Article Type:	Protocol
Date Submitted by the Author:	08-Jul-2019
Complete List of Authors:	Tuaf, Hila; University of Haifa, School of Creative Arts Therapies Orkibi, Hod; University of Haifa, School of Creative Arts Therapies
Keywords:	MENTAL HEALTH, QUALITATIVE RESEARCH, Child & adolescent psychiatry < PSYCHIATRY

A community-based rehabilitation program for youth with mental health conditions: a qualitative study protocol

Hila Tuaf[1] and Hod Orkibi[1]

[1] School of Creative Arts Therapies, Faculty of Social Welfare and Health Sciences, University of Haifa, Israel

Corresponding author: H. Orkibi, University of Haifa,

199 Aba Khoushy Av., Mount Carmel, Haifa 3498838, Israel

horkibi@univ.haifa.ac.il

Cell: +972544393621

ORCID ID: https://orcid.org/0000-0003-1498-7953

Word count: 3475.

Abstract

Introduction: In Israel, 12% of all adolescents cope with mental health conditions. Approximately 600 adolescents with mental health conditions are hospitalized each year and about 40% of them return to the hospital and are thus cut off from their daily lives and peers in the community. In contrast to adults, youth with mental health conditions in Israel are not eligible by law for rehabilitation services. Thus, the overarching goal of this qualitative study is to generate a best practice model for the implementation of community-based psychosocial rehabilitation program for this population by examining *Amitim for Youth*, the first program in Israel established in 2018 by the Israel Association of Community Centers in cooperation with the Ministry of Health, the Ministry of Education, and the Special Projects Fund of the National Insurance Institute.

Methods and analysis: Qualitative data will be collected through in-depth semi-structured interviews and focus groups. To identify themes and patterns in the data, the 6-stage thematic analysis approach will be used. A triangulation procedure will be conducted to strengthen the credibility of the findings collected by different methods and from different types of stakeholders in the program: the program's decision makers, team, intended beneficiaries and referring mental health professionals. To insure the trustworthiness of the findings, three strategies will be employed: memos writing, reflexive journaling, and member checking.

Ethics and dissemination: This study was approved by the Ethics Committee for Human Research in the Faculty of Social Welfare and Health Sciences at the University of Haifa (#455-18) and by the Chief Scientist in the Ministry of Education (#10566). All participants will sign an informed consent form and will be guaranteed confidentiality and anonymity. Data collection will be conducted in the next two years

(2019-2020). After data analysis, reports will be written, and articles will be submitted for publication.

Strengths and limitations of this study

- This is a pioneering study that will examine a community-based psychosocial rehabilitation program for youth with mental health conditions in Israel.
- The findings will offer a best practice model to meet the needs and goals of all stakeholders by addressing potential barriers and facilitators for program implementation.
- The findings can contribute to policy recommendations and legislation in the field of adolescent psychiatric rehabilitation.
- Recruiting adolescents with mental health conditions can be challenging due to their condition and motivation.
- Recruiting referring mental health professionals can be challenging due to a poor continuity of care between services.

Keywords: adolescents, youth, psychiatric rehabilitation, mental illness, mental health, recovery, community.

Introduction

Youth with Mental Health Conditions (MHC)

Adolescence is characterized by physiological, psychological and social changes that are known to be associated with many challenges.[1 2] According to Erikson's psychosocial developmental theory,[3] adolescents are in the "identity versus role confusion" stage, where they search for personal identity and strive for independence through the exploration of social roles, personal values, beliefs and goals while distancing themselves from their parents. For adolescents with MHC (i.e., who cope with a psychiatric diagnosis) this developmental task is even more complex and may lead to a lack of identity formation or a negative identity.[2] Adolescents with MHC may also have to deal with maladaptive thoughts, dysregulated emotions and behaviors which may impact their interaction with peers and family members, academic performance, and in severe cases may involve loss of contact with reality.[4] Therefore, it is important to differentiate between adolescents who are coping with age-appropriate challenges and adolescents who are coping with MHC.

Another challenge that adolescents with MHC may face is coping with stigma. The mental health literature distinguishes between public stigma and self-stigma. Public stigma refers to negative labeling (stereotype, prejudice and discrimination) of a group of people in order to distance them from society, whereas self-stigma (also termed “internalized stigma”) refers to the internalization of those negative labels in a way that changes people’s self-perception.[5] While there is ample evidence that youth with MHC experience public stigma,[6 7] self-stigma is under-investigated and insufficiently understood in adolescents with MHC.[8-10] In some studies adolescents' self-stigma has been associated with reduced self-esteem,[11] limited social interactions, secrecy, shame,[12] and less adaptive coping strategies.[13] Recent qualitative findings

suggest that adolescents' decisions to disclose their MHC is highly influenced by fear of stigma.[15 14]

A worldwide meta-analysis study showed that 13% of all adolescents cope with MHC.[16] In Israel, from 1993 to 2016 there was an increase of 130% in the number of children and adolescents who were admitted to psychiatric hospitals. In 2016, 767 adolescents aged 12 to17 were admitted to these hospitals.[17]

A bill entitled "Rights and Services for Children and Adolescents with Mental Difficulties" was submitted to the Israeli Knesset for the first time in 2014.[18] The purpose of the bill was to:

> …. ensure the rights of children and adolescents with mental disabilities to rehabilitation and care in the community, in such way as to provide an appropriate response to their special needs and enable them to integrate into the community as their peers do, while utilizing their abilities to the fullest.

The bill stressed that children and adolescents must be provided with services in the community, including leisure activities, care and guidance by counselors from the field of mental health, and include the provision of information, practical and emotional support, and assistance in imparting life and social skills.[18] However, to date this bill has not passed and youth with MHC in Israel thus remain without legislated state supported rehabilitative psychosocial services in the community.

Services for Youth with MHC in Israel

Adolescents with MHC are provided with different services than those for adults given their different needs and because the "Rehabilitation in the Community of Persons with Mental Disabilities Law of 2000" applies only to adults aged 18 and over.[19] In Israel, there are three main ministries that provide services to children and

adolescents with MHC. The Ministry of Health is responsible for the medical treatment provided by mental health clinics and in psychiatric hospitals. The Ministry of Labor, Social Affairs and Social Services is responsible for out-of-home care (post-hospitalization boarding schools). The Ministry of Education is responsible for educational services within the school system (providing personalized educational and psychological services), home-schooling and in out-of-home settings. However, the division of responsibility across the ministries is unclear and coordination is poor. Particularly problematic is the fact that there is no centralized system for creating a shared database for use by all three ministries.

The proposed study will investigate *Amitim for Youth*, the first community-based psychosocial rehabilitation program for youth with MHC in Israel. *Amitim for Youth* was established in 2018 by the Israel Association of Community Centers in cooperation with the Ministry of Health, the Ministry of Education, and the Special Projects Fund of the National Insurance Institute. The overarching goal of this study is to generate a best practice model for the implementation of community-based psychosocial rehabilitation program for youth with MHC. More specifically, the study will: (1) identify barriers and facilitators for implementation of youth psychosocial rehabilitation in the community, (2) characterize the continuity of care, or lack thereof, between the referring mental health professionals (MHP) and the program; (3) identify the needs of youth participants and their parents, program team, and referring MHP; (4) assess the satisfaction of youth participants and their parents with the overall program and its components; (5) characterize the services in the program and their value according to youth participants.

The Recovery Approach

For many years, the medical approach in the Western mental health system has been dominant. It views people with MHC as "patients" who should be hospitalized for prolonged periods to reduce their symptoms.[20] In recent decades, the rehabilitation policy of the mental health systems has been influenced by the Personal Recovery Approach which is based on the "person-centered" principle.[21] This approach focuses on integration into the community, improving quality of life, restoring a sense of control, autonomy, choice, meaning, independence as well as responsibility and hope despite the person's symptoms.[20 21] Accordingly, personal recovery is not measured in terms of a reduction in symptoms or by a return to the state prior to the mental crisis, but rather by the ability to rebuild a personal identity and live a meaningful life, with satisfying social roles and a sense of inclusion in the community.[22 23]

In Israel, the transition from the medical approach to the recovery approach has been reflected in several significant changes in the attitude of the state and society towards people with MHC. One of the main changes involved the enactment of the "Rehabilitation in the Community of Persons with Mental Disabilities Law of 2000" that provides a package of rehabilitation services to adults with MHC coping with a significant dysfunction in their life and who are eligible for these services according to criteria determined by law.[24] This law has contributed to increased integration of these individuals in the community which also reduced prolonged hospitalization and residence in institutions.[24] Changes in the attitude of the state and society to people with MHC has led to initiatives to establish a variety of programs for community-based rehabilitation. One of these programs is the *Amitim* program for adults.

Amitim for Youth

In 2001, the *Amitim* program for adults was established out of commitment to the abovementioned law for the inclusion of adults (aged 18+) with at least a 40% mental disability as determined by the National Insurance Institute.[1] The *Amitim* program is the outcome of cooperation between the Ministry of Health and the Israel Association of Community Centers and operates currently in 77 community centers across the country with about 3000 participants with MHC.

In January 2018, a pioneering *Amitim for Youth* program was launched by the Israel Association of Community Centers in cooperation with the Ministry of Health, the Ministry of Education, and the Special Projects Fund of the National Insurance Institute. An inter-ministerial steering committee that consists of representatives from each of these stakeholders was involved in the founding of the program and its initial implementation. The program provides a response to the absence of community-based psychosocial rehabilitation services in adolescents' after-school leisure time. The program consumers are adolescents (aged 12-18) who have a psychiatric diagnosis and are identified in the education system as those with "code 57". The programs' pilot began gradually in six geographical districts near psychiatric hospitals which have a youth department (Haifa and Beer-Sheva), and near special education schools for children with MHC (Rehovot, Netanya, Petah-Tikva and Carmiel). In each district, there is a coordinator who provides services to about 20 adolescents in the local community centers. Each adolescent in the program is provided with a stipend (1,200 Israeli shekels per year) for participation in leisure activities in the community. The

[1] The National Insurance Institute in Israel (NII) determines the disability level (from 0–100%) under the provisions of clauses 33 or 34 of the appendix to the NII Regulations for Determining the Level of Disability. For instance, a 40% mental health disability refers to a person in a post-psychotic condition with significant signs of impairment, limitation of work capacity, and significant disruption of behavioral, mental, and social functioning. See: https://www.health.gov.il/English/Topics/Mental_Health/rehabilitation/Pages/sal.aspx

goals of *Amitim for Youth* relate to three dimensions: youth, their family, and the wider community. For youth, the goals are to foster socialization and a sense of belonging to the community, the ability to cope with self-stigma, prevention of repeated hospitalizations and shorter hospitalization duration, return to age-appropriate functioning according to personal goals and finding a meaningful activity that will lead to satisfaction and self-actualization. For the family, the goal of the program is to provide support by the program's coordinator. Finally, the goal for members of the community at large is to change attitudes towards youth with MHC by raising awareness.

Research Questions

The following research questions will be explored. They relate to: infrastructure, implementation, and continuity of care.

Program infrastructure: (1) What characterizes the referral procedure to the *Amitim for Youth* program, and what are its barriers and facilitators factors? (2) What characterizes youth who participate in the program? (3) What is the demand for the various components offered by the program? What services are offered to the participants and how do they perceive them? What services are missing from the participants' point of view?

Program implementation: (4) how is the program implementation experienced by the stakeholders? (5) What are the barriers and facilitators factors for program implementation according to the adolescents themselves (participants and dropouts), parents, team members and referring MHP? (6) What best-practice guidelines emerge from the perspective of all actors involved?

Continuity of care: (7) What characterizes the relationship between the referring MHP and the program team in the community? (8) What best practice guidelines

emerge from the interface between referring MHP and community-based services according to the actors involved?

Methods and Analysis

The proposed qualitative study is situated between the pragmatic and constructivist paradigms.[25] The pragmatic paradigm "focuses primarily on data that are found to be useful for stakeholders".[25] It has been defined as a real-world practice-oriented framework that focuses on useful applications ("what works") and practical solutions to problems, to gather information and insights on what is relevant to the stakeholders.[26 27] The constructivist paradigm "focuses primarily on identifying multiple values and perspectives".[25] Accordingly, a close interaction with the stakeholders will be established to better understand their experiences, by taking the multiple perceptions of the different stakeholders of the program into consideration.[25 26] The two paradigms complement one another, given the fact that their boundaries are permeable.[25]

Participants

As can be seen in Figure 1, the participants in this study will be composed of the following six groups of stakeholders: (1) the program decision makers, who include the program commissioners and funders from different ministries, who are members of the program's inter-ministerial steering committee; (2) the program team, which includes coordinators and volunteers; (3) the intended beneficiaries of the program; namely, adolescents enrolled in the *Amitim for Youth* program for at least three months; (4) parents of these adolescents; (5) adolescents who dropped out of the program, and (6) referring MHP from clinics, hospitals, and schools. Each of the six groups will have about 6-12 participants which is an acceptable number in qualitative research.

-Insert Figure 1 about here-

Figure 1. The six groups of participants.

Procedure

The study will follow a *maximum variation sampling* approach of purposefully selecting a wide range of cases to document diversity and common patterns on dimensions of interest,[26] and achieve data saturation until no new relevant knowledge can be obtained from new participants. The research team will reach out by phone to the abovementioned program stakeholders (i.e., decision makers, team members, referring MHP) to invite them to participate in the study. Those who provide their written informed consent will be interviewed at their workplace or on the phone, at their convenience. Parents and adolescents will be approached by the program coordinators who will give the parents a formal letter explaining the study and an informed consent form for the parents' and/or the teens' participation. Only those parents who provide their consent will be contacted by the research team to schedule interviews at their community center or homes, at their convenience. The researchers will also attend the meetings of the program's inter-ministerial steering committee (participants in group 1 above) to document their perspectives and interactions.

Data Collection

Semi-structured in-depth interviews. Adolescents (participants and dropouts) and their parents will be invited to participate in individual interviews, to better understand their subjective experiences.[28] Examples of questions for the adolescents in the program and their parents include: What is important to you to get from the program? What do you suggest maintaining or strengthening in the program? And what do you think should change? Has the program contributed to you and how? Examples of questions for the adolescents who dropped out: How did you experience

the program? What relationship would you have liked to have with the coordinator of the program (frequency, satisfaction)? What made you leave the program, what could have helped you stay?

The referring MHP will be interviewed to characterize and evaluate recruitment processes and contacts with the program team. For example: What characterizes the adolescents you refer to the program? Describe the process of referring adolescents to the program: How is it conducted, what factors help you decide, what can be improved? Are you updated by the program team about the adolescents you referred to the program? And if so, how does this take place and for what length of time?

Members of the steering committee will be interviewed to assess the formation and implementation of the program, for example: What difficulties, challenges and dilemmas did you encounter during the setting up and implementation of the program? What can be improved and how? What is missing from the program? The interviews will be conducted by the first author (HT) and will last roughly 60-90 minutes.

Focus groups. Each of the program teams (i.e., coordinators and volunteers) will be invited to attend focus groups, to express their impressions of the training, the program implementation, as well as their relationship with the participants (adolescents and their parents) and with the referring MHP. The advantages of focus groups are that each participant can express his/her opinion, in a collaborative forum that enables an exchange of different points of view, diverse interpretations, personal and collective experiences, in an honest and open discussion, without fear of criticism or censorship.[29] Examples of questions for the coordinators and volunteers: What preparation and training did you get to work/volunteer in the program? What

difficulties, challenges and dilemmas have you encountered in the program? What is your role definition? Is it clear to you? Describe the relationship with adolescents and their parents (nature, frequency, content). Note that to minimize social desirability, individual interviews will also be conducted that may provide a deeper understanding of each coordinator's personal experience. Focus groups will be conducted by the first author (HT) and will last 90 minutes.

Sociodemographic questionnaire. Adolescents will complete a sociodemographic questionnaire on their age, gender, country of birth, religion, length of time participating in the program, and number of days a week participating in the program. The sociodemographic questionnaire for parents will include questions about socioeconomic status, marital status, their child's medical history and whether their child takes psychiatric medication.

Data Analysis

The qualitative data collected from the interviews and focus groups will be recorded and transcribed. To identify themes and patterns in the data, the 6-stage thematic analysis approach will be used, which is comprised of familiarization with and immersion in the data, coding of the data, constructing initial themes, reviewing themes, defining and naming themes, and writing up the report with illustrative data extracts.[30] This thematic analysis procedure will be used within the pragmatic and constructive frameworks. The analysis will include looking for best practice guidelines from the perspectives of the different stakeholders in the program.[26 27] Meaning and experience will be examined at both semantic and latent levels. The checklist for good thematic analysis will be used as a guide to ensure an analysis that is rigorous and robust.[31] The data analysis procedure will be conducted by the first author (HT) and assessed by second author (HO); disagreements will be resolved by

discussion. A qualitative data analysis software (ATLAS.ti v8) will be used for data management and analysis.

To strengthen the credibility of the findings, a triangulation procedure will be conducted with the qualitative data that will be collected by different methods (individual interviews and focus groups) and from different types of stakeholders in the program: the program's decision makers, team, intended beneficiaries, and referring MHP.[27 32]

Study Trustworthiness

To strengthen the trustworthiness of the findings in addition to the triangulation, three strategies will be employed, as suggested in the qualitative research literature.[32] Memo writing will be used to record decision-making, the process of meaning extraction from the data and subsequent conceptual development, as well as to facilitate continuous communication within the research team.[33] A reflexivity journal will be used to gain and maintain self-awareness of the researcher's perspective and its potential impact on the research process and interpretation of the findings.[32] To increase the credibility of the research, member checking will be held (also known as participation validation). In this procedure, the findings will be presented to the participants who will be asked to respond whether they reflect their experience, meanings, and perspectives.[32 34] Finally, to enhance the rigor of the study we will use the 32-item checklist for interviews and focus groups of the Consolidated Criteria for Reporting Qualitative research (COREQ; see online supplementary file).[35]

Discussion

To date, youth with MHC in Israel are not eligible for community-based psychosocial rehabilitation services by law, despite the rising need. No study has examined a similar community-based psychosocial rehabilitation program for youth

with MHC in Israel. The implementation of this type of program can be challenging because of the pioneering nature of the program and the specific nature of its target population: adolescents who do not only face age-related challenges but are also coping with MHC. Thus, recruiting adolescents with MHC to participate in this research might be challenging given their condition and motivation. Recruiting referring MHP to participate in the study might be complex possibly due to inconsistent continuity of care, which refers to the way mental health consumers perceive and experience their care services as connected and coherent, for example between hospital and community services.[36] In children and adolescents, coordination between different services is crucial because they are going through multiple service transitions and are therefore more vulnerable to the risks of discontinuity.

The findings will provide a best practice model to optimize the operation and implementation by service providers, enhance the service contribution to the consumers (adolescents and their parents) while meeting their needs and goals, and inform policy makers. Specific attention will be paid to addressing the potential barriers and facilitators for effective program implementation. The findings may ultimately serve as a basis for currently under-developed policy recommendations and legislation in the field of adolescent psychiatric rehabilitation.

Ethics and dissemination

The study in its current design was approved by the Ethics Committee for Human Research in the Faculty of Social Welfare and Health Sciences at the University of Haifa (#455-18), and by the Chief Scientist in the Ministry of Education (#10566). All participants will sign an informed consent form and will be guaranteed confidentiality and anonymity. Adolescents' participation will be obtained by their parents or guardians, which will also be signed by the child. Data collection will be

conducted in the next two years (2019-2020). A report in Hebrew will be submitted to the National Insurance Institute. The results will be disseminated in articles that will be written in English as part of a doctoral dissertation.

Authors' contributions: Both authors contributed equally to the conceptualization and design of the study. HT contacted the literature review that was examined and approved by HO. Both authors read and approved the final manuscript.

Funding: The study is funded by the Israeli National Insurance Institute (grant# 16343).

Competing interests: The authors declare that they have no competing interests. The funding body will have no role in data collection, analysis, interpretation, or publications.

Patient and Public Involvement: We did not involve patients or the public in our work**.**

Consent for publication: Not applicable

Word count: 3475.

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Figure 1. Six groups of participants in the study

COREQ- Consolidated criteria for reporting qualitative research: a 32-item checklist for interviews and focus groups

Tuaf, H. & Orkibi, H. (2019). A community-based rehabilitation program for youth with mental health conditions: A qualitative implementation study protocol.

Section/Topic	Item #	Checklist item	Reported on page #
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/ facilitator	1	Which author/s conducted the interview or focus group?	12
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	16
Occupation	3	What was their occupation at the time of the study?	16
Gender	4	Was the researcher male or female?	16
Experience and training	5	What experience or training did the researcher have?	16
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	10-11
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	16
Interviewer characteristics	8	What characteristics were reported about the interviewer/ facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	16
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	9,10
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	10
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	10,11
Sample size	12	How many participants were in the study?	N/A
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	10,11
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	12,13
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	12,13
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	11, 12
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	13
Field notes	20	Were field notes made during and/or after the interview or focus group?	13
Duration	21	What was the duration of the interviews or focus group?	12
Data saturation	22	Was data saturation discussed?	10

COREQ- Consolidated criteria for reporting qualitative research: a 32-item checklist for interviews and focus groups

Section/Topic	Item #	Checklist item	Reported on page #
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: Analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	13
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	13
Software	27	What software, if applicable, was used to manage the data?	13
Participant checking	28	Did participants provide feedback on the findings?	14
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	N/A
Data and findings consistent	30	Was there consistency between the data presented and the findings?	N/A
Clarity of major themes	31	Were major themes clearly presented in the findings?	N/A
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	N/A

Note: The checklist consists of items that should be included in reports on a qualitative study that has been completed. N/A = item not applicable to the current protocol of a study in the participant recruitment phase.

Checklist reference:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007; 19(6): 349-357.

BMJ Open

A community-based rehabilitation program for youth with mental health conditions in Israel: a qualitative study protocol

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-032809.R1
Article Type:	Protocol
Date Submitted by the Author:	22-Oct-2019
Complete List of Authors:	Tuaf, Hila; University of Haifa, School of Creative Arts Therapies Orkibi, Hod; University of Haifa, School of Creative Arts Therapies
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	MENTAL HEALTH, QUALITATIVE RESEARCH, Child & adolescent psychiatry < PSYCHIATRY

A community-based rehabilitation program for youth with mental health conditions in Israel: a qualitative study protocol

Hila Tuaf[1] and Hod Orkibi[1]

[1] School of Creative Arts Therapies, Faculty of Social Welfare and Health Sciences, University of Haifa, Israel

Corresponding author: H. Orkibi, University of Haifa,
199 Aba Khoushy Av., Mount Carmel, Haifa 3498838, Israel
horkibi@univ.haifa.ac.il
Cell: +972544393621
ORCID ID: https://orcid.org/0000-0003-1498-7953

Word count: 3641

Abstract

Introduction: In Israel, 12% of all adolescents have mental health conditions. Approximately 600 adolescents with mental health conditions are hospitalized each year and about 40% of them return to the hospital and are thus cut off from their daily lives and peers in the community. In contrast to adults, adolescents with mental health conditions in Israel are not eligible by law for rehabilitation services. Thus, the overarching goal of this qualitative study is to generate a best practice model for the implementation of community-based psychosocial rehabilitation program for this population by examining *Amitim for Youth*, the first program in Israel established in 2018 by the Israel Association of Community Centers in cooperation with the Ministry of Health, the Ministry of Education, and the Special Projects Fund of the National Insurance Institute.

Methods and analysis: Qualitative data will be collected through in-depth semi-structured interviews and focus groups. To identify themes and patterns in the data, the 6-stage reflexive thematic analysis approach will be used. A triangulation procedure will be conducted to strengthen the validity of the findings collected by different methods and from different types of stakeholders in the program: the program's decision makers, program team members, intended beneficiaries and referring mental health professionals. To insure the trustworthiness of the findings, three strategies will be employed: memos writing, reflexive journaling, and member checking.

Ethics and dissemination: This study was approved by the Ethics Committee for Human Research in the Faculty of Social Welfare and Health Sciences at the University of Haifa (#455-18) and by the Chief Scientist in the Ministry of Education (#10566). All participants will sign an informed consent form and will be guaranteed

confidentiality and anonymity. Data collection will be conducted in the next two years (2019-2020). After data analysis, the findings will be disseminated via publications.

Strengths and limitations of this study

- This is a pioneering study that will examine a community-based psychosocial rehabilitation program for adolescents with mental health conditions in Israel.
- The findings will inform the development of a best practice model to meet the needs and goals of all stakeholders by addressing potential barriers and facilitators for program implementation.
- The findings may contribute to policy recommendations and legislation relating to adolescent psychiatric rehabilitation.
- Recruiting adolescents with mental health conditions may be challenging due to their psychiatric condition.

Keywords: adolescents, youth, psychiatric rehabilitation, mental illness, mental health, recovery, community.

Introduction

Adolescents with Mental Health Conditions (MHC)

Adolescence is characterized by physiological, psychological and social changes that are known to be associated with many challenges.[1 2] According to Erikson's psychosocial developmental theory,[3] adolescents are in the "identity versus role confusion" stage, where they search for personal identity and strive for independence through the exploration of social roles, personal values, beliefs and goals while distancing themselves from their parents. For adolescents with MHC (i.e., who have a psychiatric diagnosis) this developmental task is even more complex and may lead to a lack of identity formation or a negative identity.[2] Adolescents with MHC may also have to deal with maladaptive thoughts, dysregulated emotions and behaviors which may impact their interaction with peers and family members, academic performance, and in severe cases may involve loss of contact with reality.[4] Therefore, it is important to differentiate between the needs of adolescents who face age-appropriate challenges and adolescents who have MHC.

Another challenge that adolescents with MHC may face is coping with stigma. The mental health literature distinguishes between public stigma and self-stigma.[5] Public stigma refers to negative labeling (stereotype, prejudice and discrimination) of a group of people to distance them from society, whereas self-stigma (also termed internalized stigma") refers to the internalization of those negative labels in a way that changes people's self-perception.[5] While there is ample evidence that adolescents with MHC experience public stigma,[6 7] self-stigma is under-investigated and insufficiently understood for adolescents with MHC.[8-10] In some studies adolescents' self-stigma has been associated with reduced self-esteem,[11] limited social interactions, secrecy, shame,[12] and less adaptive coping strategies.[13] Recent qualitative findings

suggest that adolescents' decisions to disclose their MHC is highly influenced by fear of stigma.[14 15] A worldwide meta-analysis study reported that 13% of all adolescents have MHC.[16] In Israel, from 1993 to 2016 there was an increase of 130% in the number of children and adolescents who were admitted to psychiatric hospitals. In 2016, 767 adolescents aged 12 to17 were admitted to Israeli hospitals.[17]

A legislative bill entitled "Rights and Services for Children and Adolescents with Mental Difficulties" was submitted to the Israeli Knesset for the first time in 2014.[18] The purpose of the bill was to:

> …. ensure the rights of children and adolescents with mental disabilities to rehabilitation and care in the community, in such way as to provide an appropriate response to their special needs and enable them to integrate into the community as their peers do, while utilizing their abilities to the fullest.

The bill stressed that children and adolescents must be provided with services in the community, including leisure activities, care and guidance by counselors from the field of mental health, and include the provision of information, practical and emotional support, and assistance in imparting life and social skills.[18] However, this bill has not been passed and adolescents with MHC in Israel thus remain without legislated, state supported rehabilitative psychosocial services in the community.

Note that in line with the recovery approach described below, we adopt the widely used umbrella term "mental health conditions" (rather than mental illness or psychiatric disorders or disability), which is consistent with the United Nations General Assembly 2017 report on Mental Health and Human Rights.[19]

Services for Adolescents with MHC in Israel

Adolescents with MHC are provided with different services than those for adults given their different needs and because the "Rehabilitation in the Community of Persons with Mental Disabilities Law of 2000" applies only to adults aged 18 and over.[20] In Israel, there are three main ministries that provide services to children and adolescents with MHC. The Ministry of Health is responsible for the medical treatment provided by mental health clinics and in psychiatric hospitals. The Ministry of Labor, Social Affairs and Social Services is responsible for out-of-home care (post-hospitalization boarding schools). The Ministry of Education is responsible for educational services within the school system (providing personalized educational and psychological services), home-schooling and in out-of-home settings. However, the division of responsibility across the ministries is unclear and coordination is poor. Particularly problematic is that there is no centralized database with data on service consumers across the three ministries in Israel that provide services for adolescents with MHC. This may lead to inconsistent continuity of care, which refers to the way mental health consumers perceive and experience their care services as connected and coherent, for example between hospital and community services.[21]

The Recovery Approach

For many years, the medical approach in the Westernized mental health system has been dominant. It views people with MHC as "patients" who should be hospitalized for prolonged periods to reduce their symptoms.[22] In recent decades, the rehabilitation policy of the mental health systems has been influenced by the Personal Recovery Approach which is based on the "person-centered" principle.[23] This approach focuses on integration into the community, improving quality of life, restoring a sense of control, autonomy, choice, meaning, independence as well as

responsibility and hope despite the person's symptoms.[22 23] Accordingly, personal recovery is not measured in terms of a reduction in symptoms or by a return to the state prior to the mental crisis, but rather by the ability to rebuild a personal identity and live a meaningful life, with satisfying social roles and a sense of inclusion in the community.[24 25]

In Israel, the transition from the medical approach to the recovery approach has been reflected in several significant changes in the attitude of the state and society towards people with MHC. One of the main changes involved the enactment of the "Rehabilitation in the Community of Persons with Mental Disabilities Law of 2000" that provides a package of rehabilitation services to adults with MHC with a significant dysfunction in their life and who are eligible for these services according to criteria determined by law.[26] This law has contributed to increased integration of these individuals in the community which also reduced prolonged hospitalization and residence in institutions.[26] Changes in the attitude of the state and society to people with MHC has led to initiatives to establish a variety of programs for community-based rehabilitation. One of these programs is the *Amitim* program for adults. The program was established at 2001, to comply with the abovementioned law for the inclusion of adults (aged 18+) with at least a 40% mental disability as determined by the National Insurance Institute.[1] The *Amitim* program is the outcome of cooperation between the Ministry of Health and the Israel Association of Community Centers and operates currently in 77 community centers across the country. It currently serves about 3000 adults with MHC.

[1] The National Insurance Institute in Israel (NII) determines the disability level (from 0–100%) under the provisions of clauses 33 or 34 of the appendix to the NII Regulations for Determining the Level of Disability. For instance, a 40% mental health disability refers to a person in a post-psychotic condition with significant signs of impairment, limitation of work capacity, and significant disruption of behavioral, mental, and social functioning. See: https://www.health.gov.il/English/Topics/Mental_Health/rehabilitation/Pages/sal.aspx

The literature on the recovery approach highlights the importance for services to consider adolescents' developmental needs for independence, self-determination, and self-efficacy when implementing a recovery-oriented adolescent-centered approach.[27-29] This approach, which encourages them to express their needs and opinions about the services and engage actively in their rehabilitation process,[27 28 30-33] was adopted by the *Amitim for Youth* program.

Amitim for Youth

In January 2018, a pioneering *Amitim for Youth* program was launched by the Israel Association of Community Centers in cooperation with the Ministry of Health, the Ministry of Education, and the Special Projects Fund of the National Insurance Institute. An inter-ministerial steering committee that consisted of representatives from each of these stakeholders was involved in the founding of the program and its initial implementation. The program provides a response to the absence of community-based psychosocial rehabilitation services for adolescents' after-school leisure time. The program consumers are adolescents (aged 12-18) who have a psychiatric diagnosis and are identified in the education system as those with "code 57". The programs' pilot was gradually implemented in six geographical districts near psychiatric hospitals which have a youth department (Haifa and Beer-Sheva), and near special education schools for children with MHC (Rehovot, Netanya, Petah-Tikva and Carmiel). In each district, there is a coordinator who provides services to approximately 20 adolescents in the local community centers. Each adolescent in the program is provided with a stipend (1,200 Israeli shekels per year) for participation in leisure and arts activities in the community. The goals of *Amitim for Youth* relate to three dimensions: adolescents, their family, and the wider community. For adolescents, the goals are to foster socialization and a sense of belonging to the

community, the ability to cope with self-stigma, prevention of repeated hospitalizations and shorter hospitalization duration, return to age-appropriate functioning according to personal goals and finding a meaningful activity that will lead to satisfaction and self-actualization. Another goal of the program is to provide support to the adolescents' family members (particularly parents), which is facilitated by the program's coordinator in each district. Finally, the goal for members of the community at large is to change attitudes towards adolescents with MHC by raising awareness.

The overarching goal of this study is to generate a best practice model for the implementation of community-based psychosocial rehabilitation program for adolescents with MHC. More specifically, the study will: (1) identify barriers and facilitators for implementation of adolescents psychosocial rehabilitation in the community, (2) characterize the continuity of care, or lack thereof, between the referring mental health professionals (MHP) and the program; (3) identify the needs of adolescents and their parents, program team, and referring MHP; (4) assess the satisfaction of adolescents and their parents with the overall program and its components; (5) characterize the services in the program and their value according to adolescents.

Research Questions

The following research questions will be explored. They relate to: infrastructure, implementation, and continuity of care.

Program infrastructure: (1) What characterizes the referral procedure for the *Amitim for Youth* program, and what are the barriers and facilitators factors? (2) What characterizes adolescents who participate in the program? (3) What is the demand for the various components offered by the program (including the arts)?

What services are offered to the participants and how do they perceive them? What services are missing from the participants' perspective?

Program implementation: (4) How is the program implementation experienced by the stakeholders? (5) What are the barriers and facilitators factors for program implementation according to the adolescents themselves (participants and those who withdrew), parents, program team members, and referring MHP? (6) What best-practice guidelines emerge from the perspective of all involved?

Continuity of care: (7) What characterizes the relationship between the referring MHP and the program team in the community? (8) What best practice guidelines emerge from the interface between referring MHP and community-based services according to the actors involved?

Methods and Analysis

The proposed qualitative study is situated between the pragmatic and constructivist paradigms.[34] The pragmatic paradigm "focuses primarily on data that are found to be useful for stakeholders".[34] It has been defined as a real-world practice-oriented framework that focuses on useful applications ("what works") and practical solutions to problems, to gather information and insights on what is relevant to the stakeholders.[35 36] The constructivist paradigm "focuses primarily on identifying multiple values and perspectives".[34] Accordingly, a close interaction with the stakeholders will be established to better understand their experiences, by taking the multiple perceptions of the different stakeholders of the program into consideration.[34 35] The two paradigms complement one another, given that their boundaries are permeable.[34]

Participants

As can be seen in Figure 1, the participants in this study will be composed of the following six groups of stakeholders: (1) the program decision makers, who include the program commissioners and funders from different ministries, who are members of the program's inter-ministerial steering committee; (2) the program team members, which includes coordinators and volunteers; (3) the intended beneficiaries of the program; namely, adolescents enrolled in the *Amitim for Youth* program for at least three months; (4) parents of these adolescents; (5) adolescents who withdrew from the program, and (6) referring MHP from clinics, hospitals, and schools. Each of the six groups will have approximately 6-12 participants which is an acceptable number in qualitative research.

-Insert Figure 1 about here-

Figure 1. The six groups of participants.

Procedure

The study will use a *maximum variation sampling* approach of purposefully selecting a wide range of cases to document diversity and common patterns on dimensions of interest.[35] The research team will contact the program decision makers and program team members by phone to invite them to participate in the study. The program coordinators will contact the parents and referring MHP via a formal letter explaining the study and including an informed consent form. Only those who provide their written informed consent will be contacted by the research team to schedule an interview. The MHP will be interviewed at their workplace or via the phone, at a convenient time for them. The parents and adolescents will be interviewed at their community center or homes, at a time of their convenience. The researchers will also

attend the meetings of the program's inter-ministerial steering committee (participants in group 1 above) to document their perspectives and interactions.

Data Collection

Semi-structured in-depth interviews. Adolescents and their parents will be invited to participate in individual interviews, to better understand their subjective experiences.[37] Examples of questions for the adolescents in the program and their parents include: What do you want to get from the program? What should be maintained or strengthened in the program? What do you think should change in the program? What benefits have you received from the program? Examples of questions for the adolescents who withdrew from the program: How did you experience the program? What relationship would you have liked to have with the coordinator of the program (frequency, satisfaction)? What made you leave the program, what could have helped you stay?

The referring MHP will be interviewed to describe and evaluate recruitment processes and contacts with the program team in terms of continuity of care. For example: What characterizes the adolescents you refer to the program? Describe the process of referring adolescents to the program: How is it conducted, what factors help you decide, what can be improved? Are you updated by the program team about the adolescents you referred to the program? And if so, how does this take place and for what length of time?

Members of the steering committee will be interviewed to assess the development and implementation of the program, for example: What difficulties, challenges and dilemmas did you encounter during the setting up and implementation of the program? What can be improved and how? What is missing from the program?

The interviews will be conducted by the first author (HT) and will last approximately 60-90 minutes.

Focus groups. Each of the program teams (i.e., coordinators and volunteers) will be invited to attend focus groups, to discuss their impressions of the training, the program implementation, as well as their relationship with the participants (adolescents and their parents) and with the referring MHP. The advantages of focus groups are that each participant can express his/her opinion, in a collaborative forum that enables an exchange of different points of view, diverse interpretations, personal and collective experiences, in an honest and open discussion, without fear of criticism or censorship.[38] Examples of questions for the coordinators and volunteers: What preparation and training did you receive to work/volunteer in the program? What difficulties, challenges and dilemmas have you encountered in the program? Describe your role. Is your role clear to you? How would you describe your relationship with the adolescents and their parents (nature, frequency, content)? Note that to minimize social desirability, individual interviews will also be conducted that may provide a deeper understanding of each coordinator's personal experience. Focus groups will be conducted by the first author (HT) and will last 90 minutes.

Sociodemographic questionnaire. Adolescents will complete a sociodemographic questionnaire on their age, gender, country of birth, religion, length of time participating in the program, and number of days a week participating in the program. The sociodemographic questionnaire for parents will include questions about socioeconomic status, marital status, their child's medical history and whether their child takes psychiatric medication.

Data Analysis

The qualitative data collected from the interviews and focus groups will be recorded and transcribed. The primary emphasis of this study is on identifying themes, commonalities, differences, and patterns across the dataset. Meaning and experience will be examined at both the semantic and latent levels and best practice guidelines will be identified from the perspectives of the different stakeholders in the program.[35 36] To this end, the 6-stage reflexive thematic analysis approach will be used, which is comprised of familiarization with and immersion in the data, coding of the data, constructing initial themes, reviewing themes, defining and naming themes, and writing up the report with illustrative data extracts.[39] This reflexive thematic analysis procedure will be used within the pragmatic and constructive frameworks. The checklist for good reflexive thematic analysis will be used as a guide to ensure an analysis that is rigorous and robust.[40] The data analysis procedure will be conducted by the first author (HT) and assessed by second author (HO); disagreements will be resolved by discussion. A qualitative data analysis software (ATLAS.ti v8) will be used for data management and analysis.

To strengthen the validity of the findings, a triangulation procedure will be conducted with the qualitative data that will be collected by different methods (individual interviews and focus groups) and from different types of stakeholders in the program: the program's decision makers, team, intended beneficiaries, and referring MHP.[36 41]

Study Trustworthiness

To strengthen the trustworthiness of the findings in addition to the triangulation, three strategies will be employed, as suggested in the qualitative research literature.[41] Memo writing will be used to record decision-making, the

process of meaning extraction from the data and subsequent conceptual development, as well as to facilitate continuous communication within the research team.[42] A reflexivity journal will be used to gain and maintain self-awareness of the researcher's perspective and its potential impact on the research process and interpretation of the findings.[41] To increase the credibility of the research, member checking will be held (also known as participation validation). In this procedure, the findings will be presented to the participants who will be asked to respond whether they reflect their experience, meanings, and perspectives.[41 43] Finally, to enhance the rigor of the study we will use the 32-item checklist for interviews and focus groups of the Consolidated Criteria for Reporting Qualitative research (COREQ; see online supplementary file).[44]

Patient and Public Involvement

We did not involve patients or the public in our work**.**

Discussion

Recovery-oriented adolescent-centered services in the community are crucial in the critical developmental period of adolescence, which might be even more complex for adolescents with MHC and might lead to difficulties in identity formation.[2] To date, adolescents with MHC in Israel are not eligible for community-based psychosocial rehabilitation services by law, despite the rising need. Moreover, there is no centralized database with data on service consumers that is accessible by the three ministries that provide services for adolescents with MHC in Israel, which may result in inconsistent continuity of care. Coordination between different services is crucial for adolescents with MHC who go through multiple service transitions and are therefore more vulnerable to the risks of discontinuity.[16 30 32 33 45 46]

No study has examined a similar community-based psychosocial rehabilitation program for adolescents with MHC in Israel. The *Amitim for Youth* program will

serve for a better understanding of the barriers and facilitators related to the infrastructure, implementation, and continuity of care of these services in Israel. The implementation of this type of program can be challenging because of its pioneering nature and its target population: adolescents who do not only face age-related challenges but also have MHC. Thus, recruiting adolescents with MHC to participate in this research might be challenging given their psychiatric condition. Some adolescents might be reluctant to participate out of self-stigma or low motivation whereas others might be eager to participate to share their experiences and express their voice. The findings will provide a best practice model to optimize the operation and implementation by service providers, enhance the service contribution to the consumers (adolescents and their parents) while meeting their needs and goals, and inform policy makers. Specific attention will be paid to addressing the potential barriers and facilitators for effective program implementation. The findings may ultimately serve as a basis for currently under-developed policy recommendations and legislation in the field of adolescent psychiatric rehabilitation.

Ethics and dissemination

The study in its current design was approved by the Ethics Committee for Human Research in the Faculty of Social Welfare and Health Sciences at the University of Haifa (#455-18), and by the Chief Scientist in the Ministry of Education (#10566). All participants will sign an informed consent form and will be guaranteed confidentiality and anonymity. Adolescents' participation will be obtained by their parents or guardians, which will also be signed by the child. Data collection will be conducted in the next two years (2019-2020). A report in Hebrew will be submitted to the National Insurance Institute. The results will be disseminated in articles that will be written in English as part of a doctoral dissertation.

Authors' contributions: Both authors contributed equally to the conceptualization and design of the study. HT (MA, PhD candidate, drama therapist, female) conducted the literature review that was examined and approved by HO (PhD, researcher, male). Both authors read and approved the final manuscript.

Funding: The study is funded by the Israeli National Insurance Institute (grant# 16343).

Competing interests: The authors declare that they have no competing interests. The funding body will have no role in data collection, analysis, interpretation, or publications.

Consent for publication: Not applicable.

Word count: 3641

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Figure 1. Six groups of participants in the study

COREQ- Consolidated criteria for reporting qualitative research: a 32-item checklist for interviews and focus groups

Tuaf, H. & Orkibi, H. (2019). A community-based rehabilitation program for youth with mental health conditions in Israel: A qualitative study protocol.

Section/Topic	Item #	Checklist item	Reported on page #
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/ facilitator	1	Which author/s conducted the interview or focus group?	13
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	17
Occupation	3	What was their occupation at the time of the study?	17
Gender	4	Was the researcher male or female?	17
Experience and training	5	What experience or training did the researcher have?	17
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	11
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	17
Interviewer characteristics	8	What characteristics were reported about the interviewer/ facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	17
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	10,14-15
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	11
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	11
Sample size	12	How many participants were in the study?	N/A
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	11
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	11-13,17
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	13,16
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	12-13
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	14
Field notes	20	Were field notes made during and/or after the interview or focus group?	14-15
Duration	21	What was the duration of the interviews or focus group?	13
Data saturation	22	Was data saturation discussed?	11

COREQ- Consolidated criteria for reporting qualitative research: a 32-item checklist for interviews and focus groups

Section/Topic	Item #	Checklist item	Reported on page #
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	15
Domain 3: Analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	15
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	10, 14-15
Software	27	What software, if applicable, was used to manage the data?	14
Participant checking	28	Did participants provide feedback on the findings?	15
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	N/A
Data and findings consistent	30	Was there consistency between the data presented and the findings?	N/A
Clarity of major themes	31	Were major themes clearly presented in the findings?	N/A
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	N/A

Note: The checklist consists of items that should be included in reports on a qualitative study that has been completed. N/A = item not applicable to the current protocol of a study in the participant recruitment phase. Page numbers refer to those in the Word document submitted to the journal for peer review.

Checklist reference:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007; 19(6): 349-357.

BMJ Open

A community-based rehabilitation program for adolescents with mental health conditions in Israel: a qualitative study protocol

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-032809.R2
Article Type:	Protocol
Date Submitted by the Author:	27-Nov-2019
Complete List of Authors:	Tuaf, Hila; University of Haifa, School of Creative Arts Therapies Orkibi, Hod; University of Haifa, School of Creative Arts Therapies
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	MENTAL HEALTH, QUALITATIVE RESEARCH, Child & adolescent psychiatry < PSYCHIATRY

A community-based rehabilitation program for adolescents with mental health conditions in Israel: a qualitative study protocol

Hila Tuaf[1] and Hod Orkibi[1]

[1] School of Creative Arts Therapies, Faculty of Social Welfare and Health Sciences, University of Haifa, Israel

Corresponding author: H. Orkibi, University of Haifa,
199 Aba Khoushy Av., Mount Carmel, Haifa 3498838, Israel
horkibi@univ.haifa.ac.il
Cell: +972544393621
ORCID ID: https://orcid.org/0000-0003-1498-7953

Word count: 3646

Abstract

Introduction: In Israel, 12% of adolescents have mental health conditions. Approximately 600 adolescents with mental health conditions are hospitalized each year and about 40% of them return to the hospital and are thus cut off from their daily lives and peers in the community. In contrast to adults, adolescents with mental health conditions in Israel are not eligible by law for rehabilitation services. Thus, the overarching goal of this qualitative study is to identify best practices for the implementation of community-based psychosocial rehabilitation programs for this population, by examining the first such program in Israel. *Amitim for Youth*, which was established in 2018 by the Israel Association of Community Centers in cooperation with the Ministry of Health, the Ministry of Education, and the Special Projects Fund of the National Insurance Institute.

Methods and analysis: Qualitative data will be collected through in-depth semi-structured interviews and focus groups. To identify themes and patterns in the data, a 6-stage reflexive thematic analysis approach will be used. A triangulation procedure will be conducted to strengthen the validity of the findings collected by different methods and from various stakeholders in the program: the program's decision makers, program team members, the intended beneficiaries and referring mental health professionals. To insure the trustworthiness of the findings, three strategies will be employed: memo writing, reflexive journaling, and member checking.

Ethics and dissemination: This study was approved by the Ethics Committee for Human Research in the Faculty of Social Welfare and Health Sciences at the University of Haifa (#455-18) and by the Chief Scientist in the Ministry of Education (#10566). All participants will sign an informed consent form and will be guaranteed

confidentiality and anonymity. Data collection will be conducted in the next two years (2019-2020). After data analysis, the findings will be disseminated via publications.

Strengths and limitations of this study

- This is a pioneering study that will examine a community-based psychosocial rehabilitation program for adolescents with mental health conditions in Israel.
- The findings will inform best practices to meet the needs of all stakeholders by addressing potential barriers and facilitators for program implementation.
- The findings may contribute to policy recommendations and legislation relating to adolescent psychiatric rehabilitation.
- Recruiting adolescents with mental health conditions may be challenging due to their psychiatric condition.

Keywords: adolescents, youth, psychiatric rehabilitation, mental illness, mental health, recovery, community.

Introduction

Adolescents with Mental Health Conditions (MHC)

Adolescence is characterized by physiological, psychological and social changes that are known to be associated with many challenges.[1 2] According to Erikson's psychosocial developmental theory,[3] adolescents are in the "identity versus role confusion" stage, where they search for personal identity and strive for independence through the exploration of social roles, personal values, beliefs and goals while distancing themselves from their parents. For adolescents with MHC (i.e., who have a psychiatric diagnosis), this developmental task is even more complex and may lead to a lack of identity formation or a negative identity.[2] Adolescents with MHC may also have to deal with maladaptive thoughts, dysregulated emotions and behaviors which may impact their interaction with peers and family members, academic performance, and in severe cases may involve loss of contact with reality.[4] Therefore, it is important to differentiate between the needs of adolescents who face age-appropriate challenges and adolescents who have MHC.

Another challenge that adolescents with MHC may face is coping with stigma. The mental health literature distinguishes between public stigma and self-stigma.[5] Public stigma refers to negative labeling (stereotype, prejudice and discrimination) of a group of people to distance them from society, whereas self-stigma (also termed internalized stigma) refers to the internalization of those negative labels in a way that changes people's self-perception.[5] While there is ample evidence that adolescents with MHC experience public stigma,[6 7] self-stigma is under-investigated and insufficiently understood for adolescents with MHC.[8-10] In some studies adolescents' self-stigma has been associated with reduced self-esteem,[11] limited social interactions, secrecy, shame,[12] and less adaptive coping strategies.[13] Recent qualitative findings suggest that adolescents' decisions to disclose their MHC is highly influenced by fear

of stigma.[14 15] A worldwide meta-analysis study reported that 13% of all adolescents have MHC.[16] In Israel, from 1993 to 2016, there was an increase of 130% in the number of children and adolescents who were admitted to psychiatric hospitals. In 2016, 767 adolescents aged 12 to 17 were admitted to Israeli hospitals.[17]

A legislative bill entitled "Rights and Services for Children and Adolescents with Mental Difficulties" was submitted to the Israeli Knesset for the first time in 2014.[18] The purpose of the bill was to:

> …. ensure the rights of children and adolescents with mental disabilities to rehabilitation and care in the community, in such a way as to provide an appropriate response to their special needs and enable them to integrate into the community as their peers do, while utilizing their abilities to the fullest.

The bill stressed that children and adolescents must be provided with services in the community, including leisure activities, care and guidance by counselors from the field of mental health, and include the provision of information, practical and emotional support, and assistance in imparting life and social skills.[18] However, this bill has not been passed and adolescents with MHC in Israel thus remain without legislated, State supported rehabilitative psychosocial services in the community.

Aligned with the recovery approach described below, the widely used umbrella term "mental health conditions" (rather than mental illness or psychiatric disorders or disability) was adopted, which is consistent with the United Nations General Assembly 2017 report on Mental Health and Human Rights.[19]

Services for Adolescents with MHC in Israel

Services for adolescents with MHC are different than those for adults, given their needs and because the "Rehabilitation in the Community of Persons with Mental Disabilities Law of 2000" applies only to adults aged 18 and over.[20] In Israel, there are three main ministries that provide services to children and adolescents with MHC. The Ministry of Health is responsible for the medical treatment provided by mental health clinics and in psychiatric hospitals. The Ministry of Labor, Social Affairs and Social Services is responsible for out-of-home care (post-hospitalization boarding schools). The Ministry of Education is responsible for educational services within the school system (providing personalized educational and psychological services), home-schooling and in out-of-home settings. However, the division of responsibility across the ministries is unclear and coordination is poor. Particularly problematic is that there is no centralized database with data on service consumers across the three ministries in Israel that provide services for adolescents with MHC. This may lead to inconsistent continuity of care, in terms of how mental health consumers perceive and experience their care services as connected and coherent, for example between hospital and community services.[21]

The Recovery Approach

For many years, the medical approach in the Westernized mental health system has been dominant. It views people with MHC as "patients" who should be hospitalized for prolonged periods to reduce their symptoms.[22] By contrast, in recent decades, the rehabilitation policy of mental health systems has been influenced by the Personal Recovery Approach which is based on the "person-centered" principle.[23] This approach focuses on integration into the community, improving quality of life, restoring a sense of control, autonomy, choice, meaning, independence as well as responsibility and hope despite the person's symptoms.[22 23] Accordingly, personal

recovery is not measured in terms of a reduction in symptoms or by a return to the state prior to the mental crisis, but rather by the ability to rebuild a personal identity and live a meaningful life with satisfying social roles and a sense of inclusion in the community.[24 25]

In Israel, the transition from the medical approach to the recovery approach has been reflected in several significant changes in the attitude of the State and society towards people with MHC. One of the main changes involved the enactment of the "Rehabilitation in the Community of Persons with Mental Disabilities Law of 2000" that provides a package of rehabilitation services to adults with MHC with a significant dysfunction in their life and who are eligible for these services according to criteria determined by law.[26] This law has contributed to increased integration of these individuals in the community which also has reduced prolonged hospitalization and residence in institutions.[26] Changes in the attitude of the State and society to people with MHC has led to initiatives to establish a variety of programs for community-based rehabilitation. One of these programs is the *Amitim* program for adults. The program was established at 2001, to comply with the abovementioned law for the inclusion of adults (aged 18+) with at least a 40% mental health disability as determined by the National Insurance Institute.[1] The *Amitim* program is the outcome of cooperation between the Ministry of Health and the Israel Association of Community Centers and operates currently in 77 community centers across the country. It currently serves approximately 3000 adults with MHC.

[1] The National Insurance Institute in Israel (NII) determines the disability level (from 0–100%) under the provisions of clauses 33 or 34 of the appendix to the NII Regulations for Determining the Level of Disability. For instance, a 40% mental health disability refers to a person in a post-psychotic condition with significant signs of impairment, limitation of work capacity, and significant disruption of behavioral, mental, and social functioning. See: https://www.health.gov.il/English/Topics/Mental_Health/rehabilitation/Pages/sal.aspx

The literature on the recovery approach highlights the importance for services to consider adolescents' developmental needs for independence, self-determination, and self-efficacy when implementing a recovery-oriented adolescent-centered approach.[27-29] This approach, which encourages them to express their needs and opinions about the services and engage actively in their rehabilitation process,[27 28 30-33] was adopted by the *Amitim for Youth* program.

Amitim for Youth

In January 2018, a pioneering *Amitim for Youth* program was launched by the Israel Association of Community Centers in cooperation with the Ministry of Health, the Ministry of Education, and the Special Projects Fund of the National Insurance Institute. An inter-ministerial steering committee that consisted of representatives from each of these stakeholders was involved in the founding of the program and its initial implementation. The program provides a response to the absence of community-based psychosocial rehabilitation services for adolescents' after-school leisure time. The program consumers are adolescents (aged 12-18) who have a psychiatric diagnosis and are identified in the education system as those with "code 57". The program pilot was gradually implemented in six geographic districts near psychiatric hospitals which have a child and adolescent department (Haifa and Beer-Sheva), and near special education schools for children with MHC (Rehovot, Netanya, Petah-Tikva and Carmiel). In each district, there is a coordinator who provides services to approximately 20 adolescents in the local community centers. Each adolescent in the program is provided with a stipend (1,200 Israeli shekels per year) for participation in leisure and arts activities in the community. The goals of *Amitim for Youth* relate to three dimensions: adolescents, their family, and the wider community. For adolescents, the goals are to foster socialization and a sense of

belonging to the community, the ability to cope with self-stigma, prevention of repeated hospitalizations and shorter hospitalization duration, return to age-appropriate functioning according to personal goals, and finding a meaningful activity that will lead to satisfaction and self-actualization. Another goal of the program is to provide support to the adolescents' family members (particularly parents), which is facilitated by the program's coordinator in each district. Finally, the goal for members of the community at large is to change attitudes towards adolescents with MHC by raising awareness.

The overarching goal of this study is to identify best practices for the implementation of a community-based psychosocial rehabilitation program for adolescents with MHC. More specifically, the study will: (1) identify barriers and facilitators for the implementation of adolescents psychosocial rehabilitation in the community, (2) characterize the continuity of care, or lack thereof, between the referring mental health professionals (MHP) and the program; (3) identify the needs of adolescents and their parents, program team, and referring MHP; (4) assess the satisfaction of adolescents and their parents with the overall program and its components; (5) characterize the services in the program and their value according to adolescents.

Research Questions

The following research questions will be explored. They relate to infrastructure, implementation, and continuity of care.

Program infrastructure: (1) What characterizes the referral procedure for the *Amitim for Youth* program, and what are the barriers and facilitators factors? (2) What are the characteristics of the adolescents who participate in the program? (3) What is the demand for the various components offered by the program (including the arts)?

What services are offered to the participants and how do they perceive them? What services are missing from the participants' perspective?

Program implementation: (4) How is the program implementation experienced by the stakeholders? (5) What are the barriers and facilitators factors for program implementation according to the adolescents themselves (participants and those who withdrew), parents, program team members, and referring MHP? (6) What best practices emerge from the perspectives of all involved?

Continuity of care: (7) What characterizes the relationship between the referring MHP and the program team in the community? (8) What best practices can be identified from the interface between referring MHP and community-based services according to the actors involved?

Methods and Analysis

This qualitative study is situated between the pragmatic and constructivist paradigms.[34] The pragmatic paradigm "focuses primarily on data that are found to be useful for stakeholders".[34] It has been defined as a real-world practice-oriented framework that focuses on useful applications ("what works") and practical solutions to problems, to gather information and insights on what is relevant to the stakeholders.[35 36] The constructivist paradigm "focuses primarily on identifying multiple values and perspectives".[34] Accordingly, a close interaction with the stakeholders will be established to better understand their experiences, by taking the multiple perceptions of the different stakeholders of the program into consideration.[34 35] The two paradigms complement one another, given that their boundaries are permeable.[34]

Participants

As can be seen in Figure 1, the participants in this study will be composed of the following six groups of stakeholders: (1) the program decision makers, who include the program commissioners and funders from different ministries, who are members of the program's inter-ministerial steering committee; (2) the program team members, which includes coordinators and volunteers; (3) the intended beneficiaries of the program; namely, adolescents enrolled in the *Amitim for Youth* program for at least three months; (4) parents of these adolescents; (5) adolescents who withdrew from the program, and (6) referring MHP from clinics, hospitals, and schools. Each of the six groups will have approximately 6-12 participants which is an acceptable number in qualitative research.

-Insert Figure 1 about here-

Figure 1. The six groups of participants.

Procedure

The study will use a *maximum variation sampling* approach of purposefully selecting a wide range of cases to document diversity and common patterns on dimensions of interest.[35] The research team will contact the program decision makers and program team members by phone to invite them to participate in the study. The program coordinators will contact the parents and referring MHP via a formal letter explaining the study and including an informed consent form. Only those who provide their written informed consent will be contacted by the research team to schedule an interview. The MHP will be interviewed at their workplace or via the phone, at a convenient time for them. The parents and adolescents will be interviewed at their community center or homes, at a time of their convenience. The researchers will also

attend the meetings of the program's inter-ministerial steering committee (participants in group 1 above) to document their perspectives and interactions.

Data Collection

Semi-structured in-depth interviews. Adolescents and their parents will be invited to participate in individual interviews, to better understand their subjective experiences.[37] Examples of questions for the adolescents in the program and their parents include: What do you want to get from the program? What should be maintained or strengthened in the program? What do you think should change in the program? What benefits have you received from the program? Examples of questions for the adolescents who withdrew from the program are: How did you experience the program? What relationship would you have liked to have with the coordinator of the program? What made you leave the program, what could have helped you stay?

The referring MHP will be interviewed to describe and evaluate recruitment processes and contacts with the program team in terms of continuity of care. For example: What are the characteristics of the adolescents you refer to the program? Describe the process of referring adolescents to the program: How is it conducted, what factors help you decide, what can be improved? Are you updated by the program team about the adolescents you referred to the program? And if so, how does this take place and for what length of time?

Members of the steering committee will be interviewed to assess the development and implementation of the program, for example: What difficulties, challenges and dilemmas did you encounter during the setting up and implementation of the program? What can be improved and how? What is missing from the program? The interviews will be conducted by the first author (HT) and will last approximately 60-90 minutes.

Focus groups. Each of the program teams (i.e., coordinators and volunteers) will be invited to attend focus groups, to discuss their impressions of the training, the program implementation, as well as their relationship with the participants (adolescents and their parents) and with the referring MHP. The advantages of focus groups are that each participant can express his/her opinion in a collaborative forum that enables an exchange of different points of view, diverse interpretations, personal and collective experiences, in an honest and open discussion, without fear of criticism or censorship.[38] Examples of questions for the coordinators and volunteers are: What preparation and training did you receive to work/volunteer in the program? What difficulties, challenges and dilemmas have you encountered in the program? Describe your role. Is your role clear to you? How would you describe your relationship with the adolescents and their parents (nature, frequency, content)? To minimize social desirability, individual interviews will also be conducted that may provide a deeper understanding of each coordinator's personal experience. Focus groups will be conducted by the first author (HT) and will last 90 minutes.

Sociodemographic questionnaire. Adolescents will answer sociodemographic questions on their age, gender, country of birth, religion, length of time participating in the program, and number of days a week participating in the program. The sociodemographic questionnaire for parents will include questions about socioeconomic status, marital status, their child's medical history and whether their child takes psychiatric medication.

Data Analysis

The qualitative data collected from the interviews and focus groups will be recorded and transcribed. The primary emphasis of this study is on identifying themes, commonalities, differences, and patterns across the participants. Meaning and

experience will be examined at both the semantic and latent levels, and best practices will be identified from the perspectives of the different stakeholders in the program.[35] [36] To this end, a 6-stage reflexive thematic analysis approach will be used, which is comprised of familiarization with and immersion in the data, coding of the data, constructing initial themes, reviewing themes, defining and naming themes, and writing up the report with illustrative data extracts.[39] This reflexive thematic analysis procedure will be used within the pragmatic and constructive frameworks. The checklist for good reflexive thematic analysis will be used as a guide to ensure an analysis that is rigorous and robust.[40] The data analysis procedure will be conducted by the first author (HT) and assessed by second author (HO); disagreements will be resolved by discussion. A qualitative data analysis software (ATLAS) will be used for data management and to assist data analysis.

To strengthen the validity of the findings, a triangulation procedure will be conducted with the qualitative data that will be collected by different methods (individual interviews and focus groups) and from different types of stakeholders in the program: the program's decision makers, team, intended beneficiaries, and referring MHP.[36] [41]

Study Trustworthiness

To strengthen the trustworthiness of the findings in addition to the triangulation, three strategies will be employed, as suggested in the qualitative research literature.[41] Memo writing will be used to record decision-making, the process of meaning extraction from the data and subsequent conceptual development, as well as to facilitate continuous communication within the research team.[42] A reflexivity journal will be used to gain and maintain self-awareness of the researcher's perspective and its potential impact on the research process and interpretation of the

findings.[41] To increase the credibility of the research, member checking will be held (also known as participation validation). In this procedure, the findings will be presented to the participants who will be asked to respond whether they reflect their experience, meanings, and perspectives.[41 43] Finally, to enhance the rigor of the study the 32-item checklist for interviews and focus groups of the Consolidated Criteria for Reporting Qualitative research (COREQ; see online supplementary file) will be used.[44]

Patient and Public Involvement

Patients or the public are not involved in the project.

Discussion

Recovery-oriented adolescent-centered services in the community are crucial in the critical developmental period of adolescence, which might be even more complex for adolescents with MHC and might lead to difficulties in identity formation.[2] To date, adolescents with MHC in Israel are not eligible for community-based psychosocial rehabilitation services by law, despite the rising need. There is no centralized database with data on service consumers that is accessible by the three ministries that provide services for adolescents with MHC in Israel, which may result in inconsistent continuity of care. Coordination between different services is crucial for adolescents with MHC who go through multiple service transitions and are therefore more vulnerable to the risks of discontinuity.[16 30 32 33 45 46]

No study has examined a similar community-based psychosocial rehabilitation program for adolescents with MHC in Israel. This study of the *Amitim for Youth* program will enable a better understanding of the barriers and facilitators related to the infrastructure, implementation, and continuity of care of these services in Israel. The implementation of this type of program can be challenging because of its

pioneering nature and its target population: adolescents who do not only face age-related challenges but also have MHC. Thus, recruiting adolescents with MHC to participate in this research might be challenging given their psychiatric condition. Some adolescents might be reluctant to participate out of self-stigma or low motivation whereas others might be eager to participate to share their experiences and express their voice. The findings will provide best practices recommendations to optimize the operation and implementation by service providers, enhance the service contribution to the consumers (adolescents and their parents) while meeting their needs and goals, and inform policy makers. Specific attention will be paid to addressing the potential barriers and facilitators for effective program implementation. The findings may ultimately serve as a basis for currently under-developed policy recommendations and legislation in the field of adolescent psychiatric rehabilitation.

Ethics and dissemination

The study in its current design was approved by the Ethics Committee for Human Research in the Faculty of Social Welfare and Health Sciences at the University of Haifa (#455-18), and by the Chief Scientist in the Ministry of Education (#10566). Informed consent will be obtained from all participants and they will be guaranteed confidentiality and anonymity. Consent for the adolescents' participation will be also obtained from their parents or guardians via written consent. Data collection will be conducted in the next two years (2019-2020). A report in Hebrew will be submitted to the National Insurance Institute. The results will be disseminated in articles that will be written in English as part of a doctoral dissertation.

Authors' contributions: Both authors contributed equally to the conceptualization and design of the study. HT (MA, PhD candidate, cognitive behavioral drama

therapist, female) conducted the literature review that was examined and approved by HO (PhD, researcher, male). Both authors read and approved the final manuscript.

Funding: The study is funded by the Israeli National Insurance Institute (grant# 16343).

Competing interests: The authors declare that they have no competing interests. The funding body will have no role in data collection, analysis, interpretation, or publications.

Consent for publication: Not applicable.

Word count: 3646

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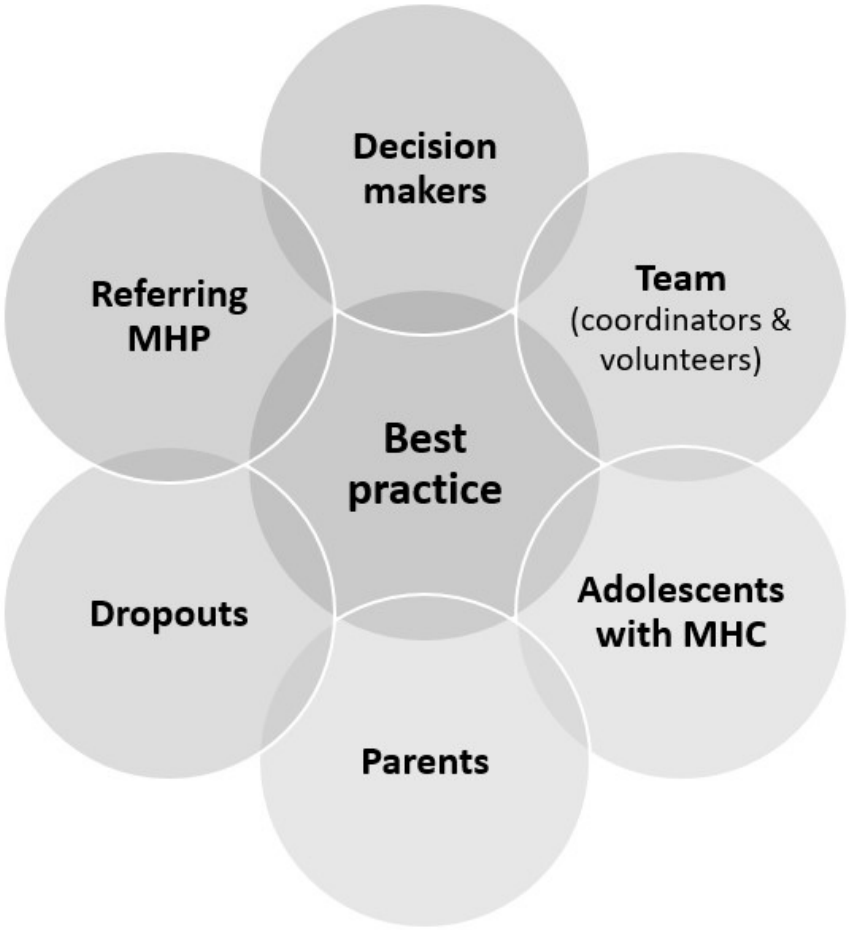

Figure 1. Six groups of participants in the study.

166x163mm (96 x 96 DPI)

COREQ- Consolidated criteria for reporting qualitative research: a 32-item checklist for interviews and focus groups

Tuaf, H. & Orkibi, H. (2019). A community-based rehabilitation program for adolescents with mental health conditions: A qualitative study protocol.

Section/Topic	Item #	Checklist item	Reported on page #
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/ facilitator	1	Which author/s conducted the interview or focus group?	12,13
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	17
Occupation	3	What was their occupation at the time of the study?	17
Gender	4	Was the researcher male or female?	17
Experience and training	5	What experience or training did the researcher have?	17
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	11-12
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	17
Interviewer characteristics	8	What characteristics were reported about the interviewer/ facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	17
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	10
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	11
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	11-12
Sample size	12	How many participants were in the study?	N/A
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	11-12
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	13
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	13
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	12-13
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	13
Field notes	20	Were field notes made during and/or after the interview or focus group?	14
Duration	21	What was the duration of the interviews or focus group?	12-13
Data saturation	22	Was data saturation discussed?	11

COREQ- Consolidated criteria for reporting qualitative research: a 32-item checklist for interviews and focus groups

Section/Topic	Item #	Checklist item	Reported on page #
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: Analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	14
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	14
Software	27	What software, if applicable, was used to manage the data?	14
Participant checking	28	Did participants provide feedback on the findings?	14-15
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	N/A
Data and findings consistent	30	Was there consistency between the data presented and the findings?	N/A
Clarity of major themes	31	Were major themes clearly presented in the findings?	N/A
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	N/A

Note: The checklist consists of items that should be included in reports on a qualitative study that has been completed. N/A = item not applicable to the current protocol of a study in the participant recruitment phase. Page numbers are for the document submitted for review.

Checklist reference:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007; 19(6): 349-357.