

A comprehensive educational program for promoting Sexual Knowledge and Social Skills Mild Intellectually Disabled Teenagers in Puberty: protocol for a mixed methods study

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Abstract

Background: Puberty is an important period for teenagers with intellectual disability (ID). In this period sexuality education and increasing social skills of adolescent and education of mothers become absolutely vital. The current research aimed to present a comprehensive educational program for promoting sexual knowledge and social skills mild intellectually disabled teenagers in puberty.

Methods: This study is a sequential exploratory (qualitative – quantitative) mixed methods design that consists of three consecutive phases. In this study, following a qualitative approach, the researchers will explain state of sexual knowledge and social skills mild intellectually disabled teenagers in puberty. In the second phase, researchers will design an appropriate and comprehensive educational program for promoting sexual knowledge and social skills of MID adolescents and the education of their mothers. The suggested program of expert panel is approved based on prioritization guidelines and will be finalized for the execution. In the third stage, the effectiveness of educational program will be investigated in a semi-experimental study.

Conclusions: Findings revealed that the educational program is appropriate MID adolescents and their mothers and will increase their sexual knowledge and social skills in puberty. Educational programs are important for teenagers with MID and their mothers. Family plays an important role in puberty of these adolescents.

Plain English Summary

Boys and girls with mild intellectually disability (MID) go through puberty and other developmental changes similar to normally developed individuals. They are often deprived of parental support and training so that they could adapt themselves to the new period. Sexual demonstrations can provide grounds for abusing intellectually disabled teens. Impairments in social skills and receiving no training may eventuate inappropriate behavior. Some evidence shows these teens are ridiculed in family parties, streets, neighborhoods and their care homes.

In the current study, the researcher presents the promotion of sexual knowledge and social skills of mild intellectually disabled adolescent girls and boys using a qualitative approach that in the first phase explain state of sexual knowledge and social skills mild intellectually disabled teenagers. In the onset of the second phase, a comprehensive educational program is provided to promote sexual knowledge and social skills for mild intellectually disabled adolescent girls and boys. In addition to the qualitative studies, some related papers and texts are reviewed. The suggested program of expert panel is approved based on the prioritization guidelines. In the third phase, the impact of an educational program for teenagers with MID and their mothers was studied in the increasing sexual knowledge and social skills. The results of the present study are expected to combine approaches, providing a comprehensive educational program to promote sexual knowledge and social skills for adolescents and mothers, enhance sexual knowledge and improve the social skills of these girls and boys. Lack of awareness and

readiness in adolescence can lead to various problems for girls and boys with disabilities. Therefore, education is essential for parents and adolescents.

Background

Puberty, also known as pubescence, is a biological process of sexual maturation. In human beings, this process occurs sometime between the age of eight and sixteen. During this period, one can detect hormones - chemical messengers in the blood, triggering the occurrence of secondary sex characteristics and other physical changes typically related to puberty. Various factors can affect the puberty including nutrition, physical activity, weather, and stress [1] the most important of which are the genetic factors. Puberty is the first stage of adolescence and is among the possible challenges in this period. The physical changes during puberty can affect mental, behavioral, and social performances of adolescents [2]. Puberty is one of the time periods in which there is the highest risk for behavioral, social and sexual problems [3].

Puberty is a vital period for boys and girls with intellectual disability (ID). The growth pattern of adolescents with MID is the same as normal adolescents [4-5]. Most ID adolescent lack sufficient knowledge of such biological changes, and often little information is given about what is happening to them during this period [6-7]. During the adolescence, boys and girls with intellectual disabilities differ in their biological age in addition to social, emotional, intellectual, and experiential ages. Sexual desires usually coincide with the disability [8]. Factors such as awareness, attitudes and parenting styles play significant roles in the sexual and mental health of these adolescents. During puberty, MID girls will go through their period or menstrual cycle similar to girls with no intellectual disability; however, MID girls encounter a number of challenges in overcoming their personal and hygienic problems [1]. Certain studies have indicated that MID girls do not generally have sufficient information on menstruation and may encounter many problems including anxiety, aggression and negative attitudes toward menstruation and its hygienic problems [9].

In puberty period, it is vital to have sexual knowledge including physiological knowledge, knowledge about sexual intercourse, pregnancy and contraception, sexuality, sexual abuse, and sexually transmitted diseases as well as sexual identity. In the above-mentioned areas, teenagers with MID have received little information [10-11].

Research findings show that girls and boys with MID require more education on sexuality as they are more susceptible to sexual abuse especially in puberty period. Although they experience the same sexual requirements and developments as others, their intellectual disability can cause difficulties for their families and themselves [12-13]. The growth of sexuality begins from the moment the parents become aware of the child gender and label them as male or female. Thus, hitting puberty, regardless of the mental age of girls and boys with MID, is a sign showing that they have passed the childhood stage and require adult support to attain sexually acceptable behavior in accordance with the norms and

expectations of society. Accordingly, ID adolescents ought to be trained by parents and educators before and after puberty [14].

Teenagers experience certain rapid changes in their bodies resulting in their discomfort and anxiety about their appearance. They might also experience physical anxiety when one part of the body does not suit the rest. Parents should talk about physical changes with teens and be responsive to their questions [15-16]. Puberty is a difficult and confusing time for the teenagers with MID and the physical changes associated with puberty can be particularly uncomfortable for such teenagers and technically challenging to health care givers. They experience physical and emotional changes similar to their peers, but depending on the severity of the disability, they may not perceive the new changes. They require learning about changes and hygiene skills [17]. Teenagers with MID should be familiar with their body organs and understand the normality of their physical changes. It seems that they need to understand rules about relationships, personal boundaries, and sexuality [14]. Sexual health encompasses physical, emotional, spiritual and social dimensions. The sexual health of the average person is crucial and there are regular reports of exposure to sexual abuse [18-20]. Some of the factors that increase the risk of sexual abuse in MID adolescents may include feelings of powerlessness, lack of communication skills, and inability to protect the person due to lack of education and resources. Disorders in social skills and inadequate education lead to inappropriate behavior when confronted with the opposite sex, which in turn may pose a risk to them [21].

Education about basic reproductive physiology, gender differences, and sexual abuse has been theorized to increase the ability of adolescents with ID to recognize and report abuses perpetrated against them [22-23].

The physical and mental health of these adolescents and their education in puberty are influenced by various sub-systems including personal (such as parents, caregivers and friends), social and cultural environments [24]. They do not often have necessary and proper personal skills for safety against sexual abuse. They need personal safety and educational programs to reduce this risk. The goal of self-protection skills and educational programs is to teach these patients to identify a potentially dangerous situation, respond safely to the situation by verbally refusing and/or leaving the situation, and report the situation [25-28].

Some studies have indicated that sexuality education and the increased sexual knowledge are quite essential in declining the risk of sexual abuse. In the program, the participants are trained about their body parts, reproduction, relationships, male and female roles, contraception, and sexually transmitted diseases (STDs). Furthermore, it seems essential to invest on family planning associations for teaching parenting style [12, 24, 26, 29, 30-31]. Garwood and McCabe 2000 used the Co-Care program and the Family Planning Victoria (FPV) program to teach sexuality knowledge to children and adults with intellectual disabilities. The Co-Care program encompassed feelings, body language, social skills, human life cycle, puberty, body awareness, private and public behavior, sexual relationships, conception,

pregnancy and childbirth, contraception, menstruation, and protective behaviors. According to the results, the participants increased their sexual knowledge at post training [32].

Developing a full repertoire of social skills is critical for successful functioning in life. Research indicates that social skills can be developed and improved through a variety of instructional methods [33]. In the case of an adult with a mental disability, intensive training is required to stimulate appropriate social behaviors. Therefore, education should begin at an early age. Family, teachers, friends, and the community are generally responsible for teaching the social skills the intellectually disabled [34-35].

Individuals with MID often show social impairments during puberty and adolescence. In a study, the program merged the behavioral skills training and video modeling to teach target social skills placed an emphasis on the accurate demonstration of three target social skills in adolescents with ID. The skills included expressing requests and requirements, having conversation, and turn-taking with the intervention. The results revealed indicated great improvements for the participants in such skills [36]. Therefore, interventions aiming to decrease an individual's vulnerability through social skills development are critical components of any rehabilitation plans [37].

Studies have shown that social skills interventions and classroom supports are effective for students with MID, as such interventions have been verified to reduce the risk of developing mental disorders. The strategies for teaching social skills such as modeling, role playing, positive reinforcement, practice/rehearsal, incidental teaching, prompting, and coaching would help the adolescents begin and extend positive social relationships with others [38-41].

The in social skill impairments at the time of puberty and lack of adequate training lead to improper behaviors in adolescents with MID when facing the opposite sex. The results of a number of studies show that some problems such as inappropriate sexual behavior lead to serious concern for parents of MID adolescents and sometimes even sexual abuse. High social skills can positively affect the sexual behavior [42-43].

Objectives

Each phase has an objective as follows:

Objectives of the first phase: qualitative study

The explanation of social skills and sexual knowledge in the education of ID adolescent girls and boys and mothers.

Objectives of the second phase: program design

Outlining an introductory interventional program based on extracted data from the first phase and reviews.

Validation of the interventional program by a number of experts.

Objectives of the third phase: quantitative study

Investigation on the effects of educational programs for adolescents and their mothers on increasing of the sexual knowledge and social skills of teenager's girls and boys with mild intellectual disability (MID) during puberty.

Methods/design

This study is a sequential exploratory (qualitative – quantitative) mixed methods design that consists of three consecutive phases. Following a qualitative approach, the researchers in this study will explain the facilitators and strategies associated with promoting sexual knowledge and social skills of teenagers with (MID) during puberty. In the second phase, the researcher will design an appropriate interventional program by using the results of the first phase and literature reviews. To this end, a literature review of papers and texts will be used in addition to the results of qualitative study. Then, the suggested program will be authenticated based on the prioritization guidelines. In the third stage, the efficacy of interventional program on increasing of the sexual knowledge and social skills of teenager's girls and boys with MID will be investigated in a semi-experimental study. The collected data will be processed by SPSS Version 23.0 software and analyzed with descriptive-analytic statistical methods (Fig. 1).

First phase: qualitative study

At this phase, the researcher attempts to discover strategies and training methods to design an interventional program for teenager's girls and boys with MID for increasing their sexual knowledge and social skills in puberty. This study is conducted via qualitative content analysis method.

Participants in the qualitative phase

Research community of the first phase comprises books, intervention guide, articles, mild intellectual disability adolescent girls and boys, parents, siblings, teachers, psychologists, consultants, specialist of children with special needs, professors, all of whom have the experience of dealing with problems of mild intellectually disabled adolescent.

Sampling method

In the present study, the participants are selected with a purposeful sampling method. They are selected according to the content, age, educational level, work experience, socioeconomic condition, and the pertinent research.

Inclusion criteria for participants

The inclusion criteria include the willingness to participate in the study and with informed consent for sharing information and participating in interviews. Ability to understand and express the experiences

and Iranian nationality. For psychologists, consultants, specialist of children with special needs, having at least 4 years of working experience is necessary.

Also, to conduct the research, the following criteria and limitations were considered:

Articles published between 2000 and 2017, intervention articles included statistical population and sample, Studies involving at least one adolescent ages 12 to 16 years with mild intellectual disability, Studies about the effects of educational, behavioral, and psychological interventions and the consequences of the interventions were clearly conducted in theses, handbooks, interventional guides and educational programs.

Research environment

The participants have access to welfare and rehabilitation centers, exceptional education schools, consulting centers, psychological clinics, research institutes, university of psychology. The interviews will be performed at the time and place of the participants' desire for their ease and comfort and more cooperation of them.

Data collection process

After selecting participants, the researcher will introduce the main objectives of the study. Then, the researcher will receive written consent regarding the participation in the research, further interviews, and recording the interviews. The researchers will ensure that the participants have their freedom to discontinue their cooperation with the study whenever they want. After obtaining a verbal and written consent from the participants, the interviews will be recorded using iPhone device. In case the sound recording is not allowed, interviews will be conducted by taking notes. Data will be collected through individual, in-depth, open, interviews, focus group discussions and field notes. The concerns of participants, especially parents, teachers, and siblings, were sought to gain the necessary confidence. The interviews will begin with the open questions for example "What is sex knowledge? What information should a teenager with MID have about sex in puberty? Can these people increase sexual knowledge? What methods can be used for sexual education to girls and boys with MID? What social skills should be taught to girls and boys with MID and by what method? What role will the family play in the training process? Then, according to the responses, the direction of the interview was guided. The data collection will continue until no new data code will emerge in the interviews.

Data analysis

Data will be analyzed using conventional content analysis. This method tends to reduce information and provide a detailed description of an issue (44). The researcher gradually summarizes the data under study to finally reach the most important concepts and themes relevant to the research topic. After recording the interviews, researcher explored the data to obtain a full understanding of the interviews. The encryption process was used in which encoding evidence grouping and naming ideas reflects broader perspectives. After generating the codes using the induction method, similar codes are merged and those

with similar meanings fall into the same category to create subsets which is conducted by constantly comparing all the data. Finally, using the inductive process, similar subgroups fall into the main category. There are a variety of procedures for the thematic analysis process.

Accuracy and reliability of qualitative data

To have a reliable analysis, dependability, credibility, and transferability standards will be used [45]. Also, in order to improve the credibility of this study, a combination of data gathering methods such as individual interviews in different locations and times, focus group discussions, and field noting and the maximum variation in selecting the participants will be used. To study the validity of the findings, some examples of code extraction methods and their corresponding interview narratives will be reviewed by an external supervisor. For transferability, findings will be presented to people who have similar characteristics with the participants in order to compare the results of this study with their own experiences. Regarding verification, the researcher will explain the whole procedure. In order to verify the coding procedure, some of the research colleagues and professors, who are acquainted with qualitative research analysis and do not want to participate in this research, are asked to review the procedure.

Second phase: designing interventional program

The purpose of this phase is to design an intervention program to increase the sex knowledge and social skills of MID adolescent in puberty. In this phase, educational approaches and techniques are extracted based on the results of qualitative phase and studies conducted and their review. The method of review will be narrative review electronic and library resources including reference books, theses and experts and based on the intervention guide of Intervention Guide of Social Skills Improvement System (IGSSIS) and Intervention Guide for Behavioral and Emotional Issues (IGBEI) and other guidelines. Databases that will be used to search and identify related articles, are PubMed, Google scholar, SID, Scopus, Science Direct, Springer, Cochrane Library, MEDLINE, Elsevier and ProQuest. All the studies published between 2000 to 2017, both in English and Persian languages with qualitative, quantitative, and mixed methods study and with the keywords: Adolescence, Puberty, Intervention, Treatment, and Therapy, sex knowledge, sexual abuse, social skills, Communication, Parental training and parenting styles were investigated related to MID adolescents and their mother.

Holding a panel of experts

At this stage, the drafting of the strategies extracted from the qualitative research and review of the text will be prioritized using the decision matrix. In this way, these strategies will be presented to a number of experts in the first Delphi round in terms of cost, ease of implementation, timing and effectiveness; and for each dimension, a score between 1 and 3 will be considered. After completing their decision matrix and gathering opinions, the priority-based strategies given by each member will be prioritized for each dimension of interventions and strategies. Then, an intervention program will be designed for the highest priority strategies and in the second round of Delphi, a preliminary version of the proposed intervention program will be designed, presented, and evaluated in panel discussion in the presence of the research

team and experts (including psychiatric specialists, psychologists, teachers, consultants, specialist of children with special needs, and professors). A few days before the meeting, a copy of the proposed intervention program will be accessible to the panel members to write their comments. Then, based on the panel members' views, the corrections will be made to the designed intervention program, and subsequently implemented in the quantitative phase (Phase III of the study).

Third phase: quantitative study

Type and direction of the quantitative study

The quantitative phase of the research will be conducted via a four-group semi -experimental study.

The studied population

The targeted populations for quantitative study consisted of all boys and girls with MID from Exceptional Public Schools and their mothers.

Research sample

The research sample included girls and boys adolescents with MID and their mothers, selected through cluster sampling.

Research environment

This study was conducted in Exceptional Public Schools of girls and boys with MID in Yazd, Iran. The reason for selecting such kind of environment is the easy access to MID adolescents and their mothers.

Sample size

Sample size will be 15 participants in each group considering 95% confidence interval, 80% trial power, $d = 7$ and $S = 14$.

Sampling method

This clinical trial has two intervention groups and two control groups, selected through cluster sampling. At the beginning of each area, one schools for girls and boys with MID were selected and then from each school, the selected number of classes and in the next step number of students were selected randomly.

The inclusion criteria

Inclusion criteria of each group consisted of the adolescents with MID (IQ=60-70 with Wechsler Intelligence Scale for Children WISC-IV), between the age of 12-16, healthy eyesight and hearing, and literate parents (more preferable for the research).

Exclusion criteria

Non-cooperation and parental dissatisfaction with continuing work and failure to receive 50% of the intervention for any reason.

Study variables

In this study, the designed interventions were considered as an independent variable. On the other hand, sexual knowledge (SK) and social skills (SS) of mild intellectually disabled adolescent girls and boys were be deemed as dependent variables.

Data collection

The tools used in the quantitative phase of this research about sexual knowledge are researcher-made questionnaires. Following the preceding studies in this area, a 39-item questionnaire including five subscales (physiology knowledge, sexual knowledge, pregnancy, sexually transmitted diseases and sexual identity) was separately designed for girls, boys and mothers in 3 separate forms. In completing the questionnaire items, the respondents had three options including “right”, “wrong” and “I don’t know”. Each correct answer scored one point. In this scale higher scores are favorable. To determine the content validity of the survey, the Lawshe’s method was employed and the CVR and CVI indices were calculated. Additionally, a number of experts and professors were kindly asked to express their opinions regarding the contents after which the necessary changes were incorporated. The content validity ratio (CVR) was separately calculated for each item, the results of which ranged from 0.8 to 1. To calculate the content validity index (CVI), the research items were assessed in terms of relevance, clarity and simplicity. The experts expressed their views using a 4-point scale ranging from 1 to 4 as having a minimum (1) or maximum (4) degree of relevance, clarity and simplicity. In terms of face validity, certain items lacked simplicity or clarity hence the necessary changes were made accordingly. To make some items more understandable for the ID adolescents, the researcher used certain images. To measure the reliability of the survey, the test-retest method was used within a 2-week interval for girls and boys with MID. The correlation coefficients turned out to be 0.80 and 0.87 for the boys and girls, respectively. To further evaluate the internal consistency, the Kuder-Richardson method was used, the results of which turned out to be 0.81 and 0.83 for the boys and girls, respectively.

The SSIS questionnaire, prepared by Gresham and Elliott (2008), contains 79 multiple choice items including four options of “never”, “seldom”, “often” and “always”, coded as 3, 2, 1 and 0, respectively. The questionnaire examines the social and behavioral skills. Each of these scales in turn includes a number of subscales and each of which is assessed by a number of specific items. The “Social Skills” scale consists of seven subscales (Communication, Cooperation, Assertion, Responsibility, Empathy, Engagement, and Self-Control). In this scale higher scores are favorable. The “Behavioral Problems” Scale consists of 4 subscales (Externalized, Bullying, Hyperactivity/Inattention and Internalization). In this scale lower scores are favorable. The questionnaire can be used for the age group of 3 to 18 years and should be completed by parents. In this study, the questionnaire was administered to a group mothers of teenagers with MID, the results of which revealed that it enjoyed an appropriate reliability with

the Cronbach's Coefficient Alpha of 0.83. Research shows that the strength of SSRS is retained in the SSIS and the validity scales improve the psychometric properties [46-47].

The implementation method

This study was approved by the University of Isfahan. The study protocol was in accordance with the ethics committee criteria and informed consent was obtained from all participants in the study. The pre-test was administered to both mothers and adolescents and then the experimental group was exposed to the educational program. In the pre-test and post-test of the control and experimental groups, the SSIS scale was given to the students' mothers, and after explaining the aims and benefits of the research and the method of filling out the questionnaire, sexual knowledge about sexual knowledge was presented. Questionnaire (SKQ) was completed by boys and girls with MID and their mothers with researcher's guidance. The program aimed to teach sexual knowledge for 23 sessions while 15 sessions were allocated for teaching social issues via educational tools. Each session took 60 minutes and used of individualized education program. In each session, according to the content, the researchers used the card training, educational stories, and educational books with illustrations, role play and video training. The learning of student was examined through workbooks and used the reinforcement to increase learning. In training sessions, educational booklets and power point presentations were used for mothers to answer their questions. The control group was not exposed to such an intervention. Following the intervention sessions, the adolescents along with their mothers in both groups were given a post-test. It is worth mentioning that the results of the follow up was obtained with a 1- month interval.

Data analysis

The collected data was analyzed via descriptive statistical methods (mean, standard deviation, minimum and maximum) and inferential statistics (Multivariate covariance analysis (MANCOVA), and Mixed-Design analysis of variance) and by using SPSS 23 software.

Integration of the qualitative and quantitative data

The results of the qualitative and quantitative phases of the study were integrated and finally an interventional program was provided for MID teenagers and their mothers to increase the sexual knowledge and social skills in puberty.

Discussion

The findings of the study reveal that educating teenagers and their mothers can be effective in reducing social problems and increasing the sexual knowledge of girls and boys with MID. This is consistent with the results of multiple studies [38-43].

Adolescents with MID are at risk of their needs being ignored during puberty. Unfortunately, many families do not make educational plans for their children's puberty. Furthermore, many teenagers suffering from MID receive inappropriate education and training on puberty at special schools [5, 48-49].

MID adolescents need intensive training to inculcate appropriate social and sexual behaviors. When they behave in inappropriate social situations, they will often be rejected, isolated by peers. They are unable to cope with life's challenges or respond effectively to social interactions. They may not have a good understanding of effective relationships in social situations. They do not know how to behave in specific situations. Moreover, they have difficulty identifying and understanding textual situations and clues. Therefore, social skills are essential for these teens to have a comfortable life in the community.

Sexual knowledge is also very important for boys and girls with MID. For instance, it is important that they be trained on the meaning of private and public places, private and general organs of the body, sexual abuse, and self-care skills [50-51]. Numerous studies show that the knowledge about sexual issues in individuals with MID is lower than that in normal people. These individuals cannot obtain this knowledge from others. They are not able to read and comprehend books and magazines as sources of information in this regard. Usually, there is not enough opportunity in their schools to teach these matters as well as features of their own sex and distinctions between the two sexes. We need to consider that adolescents with MID are more exposed to sexual abuse than are normal people. Thus, education is necessary for them in puberty [52-53].

Conclusion

According to the importance of puberty period and increasing the sexual knowledge and social skills, parents should inform adolescents with MID of the emotional fluctuations occurring in connection with what is going on in the body. Lack of knowledge can raise the risk of social, behavioral, and sexual problems. In many families, there is not enough opportunity to educate such issues in addition to gender education and gender differences, thus it is essential for families and their children to receive education before puberty. The cultural and educational difference should be considered in different countries. It is suggested that researchers conduct further investigations about the different educational approaches related to teachers and parents of ID teens regarding the requirements of puberty in consistence with the cultural norms of the that society.

Declarations

Availability of Data and Materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Authors' contributions

All the authors contributed to the conception and design of the study. LA drafted the first version of the manuscript. MM, SF, AA, revised the manuscript. MM, AA, critically reviewed the manuscript for important intellectual content. All authors approved the final version.

Ethics approval and consent to participate

The Ethics Committee of the Isfahan University, Isfahan, Iran approved the protocol of this study. Written informed consent will take from each participant.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Abbreviations

MID: Mild intellectual disability, ID: Intellectual disability, SSIS: Social skills improvement system, SKQ: Sexual knowledge questionnaire.

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Figures

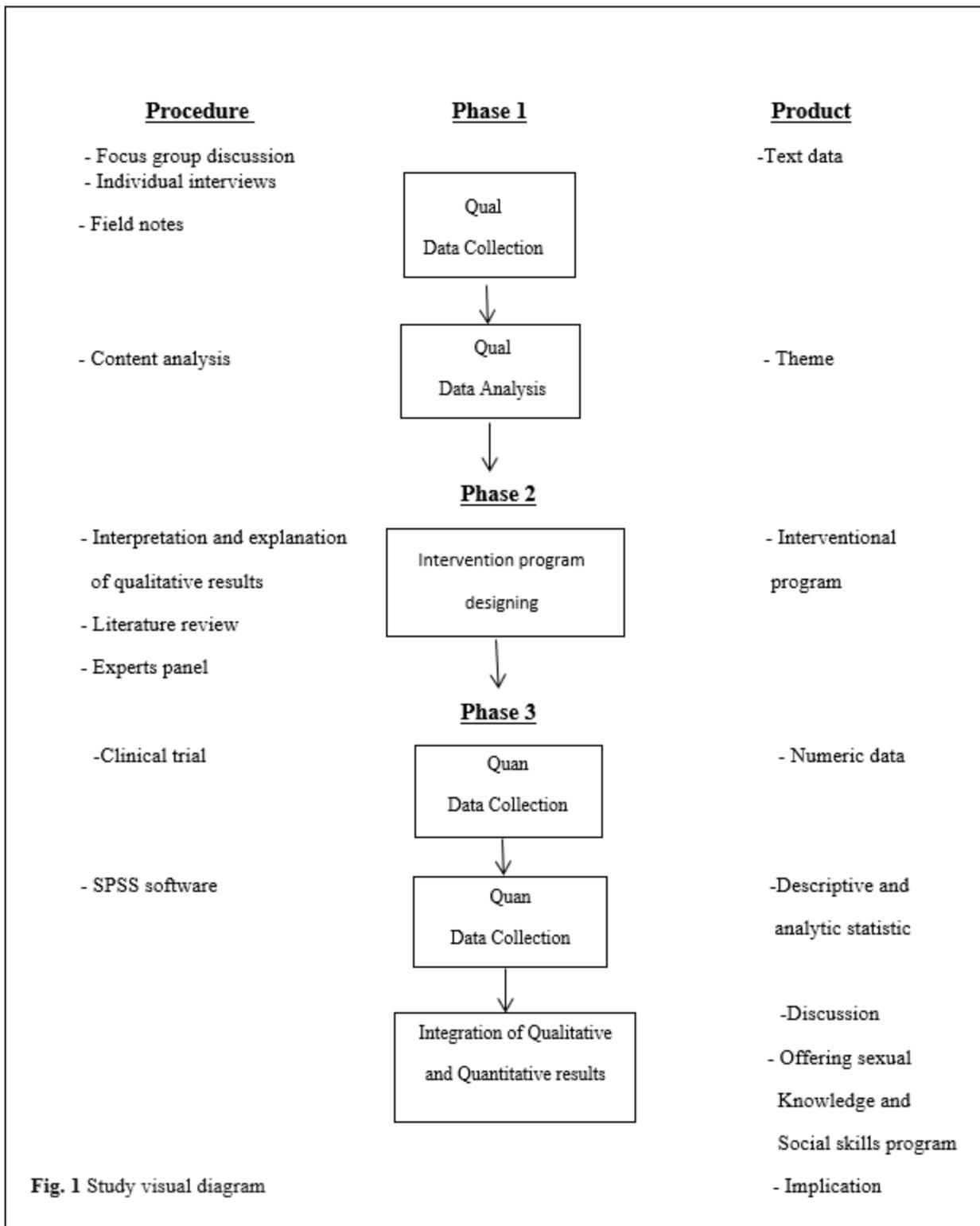


Fig. 1 Study visual diagram

Figure 1