

THE STUDY OF THE EFFECTS OF GROUP EDUCATION
AND COUNSELING ON THE SELF-CONCEPT OF
ADOLESCENTS WITH TURNER'S SYNDROMEE

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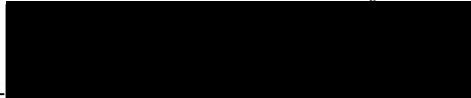
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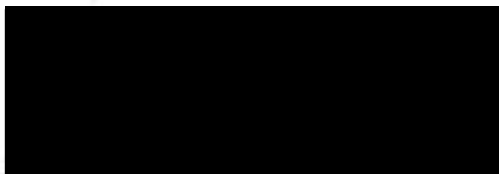
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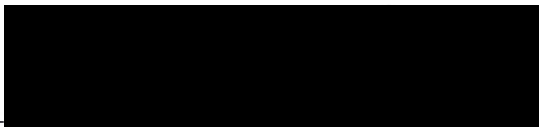
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1.a.

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CHAPTER I

INTRODUCTION

Individuals with gonadal dysgenesis have streaks of connective tissue instead of gonads. They lack germ cells, have short stature, and may also have any of a group of somatic anomalies which along with short stature are termed the Turner stigmata. These stigmata include craniofacial, neck, chest, cardiovascular, renal, skin, and skeletal abnormalities (see Table 1). Gonadal dysgenesis accompanied by any of these stigmata is commonly called Turner's syndrome. Turner's syndrome is associated with monosomy for the X chromosome or structural rearrangements of the X chromosome (Simpson, 1976).

The short stature, sterility, and sometimes dysmorphic features associated with Turner's syndrome can make adolescence an especially trying time for affected girls. Many concerns of adolescence deal with the individual's conception of self, or self-concept. Self-concept may be defined as conscious, cognitive perception and evaluation by individuals of themselves (Zahran, 1971); it is their thoughts and opinions about themselves (Rice, 1978). Self-concept also implies a developing awareness of who and what one is. It describes what individuals see when they look at themselves, in terms of their self perceived physical characteristics, personality skills, traits, roles, and social statuses. It may be described as the system of attitudes they have about themselves (Thornburg, 1975). It is assumed that adolescents with Turner's syndrome experience the same developmental problems as their age mates, as well as the additional stresses of being adolescents who are different from their peers.

Somatic Features Associated with Turner's Syndrome

Growth

decreased birthweight and birth length
decreased adult height (mean 141 cm.)

Intellectual function

performance IQ less than verbal IQ
space-form blindness

Craniofacial

premature closure of sutures causing brachycephaly
abnormal pinnas
receding mandible
epicanthal folds (25%)
high-arched palate (36%)
abnormal dentition
visual anomalies, usually strabismus
auditory deficits; sensorineural or secondary to middle ear infections

Neck

webbing of the neck (46%)
short broad neck (74%)
low posterior hairline (71%)

Chest

rectangular contour (shield chest) (53%)
apparent widely spaced nipples
tapered lateral ends of clavicle

Cardiovascular

coarctation of aorta or ventricular septal defect (10-16%)

Renal (38%)

horseshoe kidney
unilateral renal aplasia
duplication ureters

Skin and Lymphatics

pigmented nevi (63%)
lymphedema (38%) due to hypoplasia of superficial vessels

Nails

hypoplasia or malformations (66%)

Skeletal

cubitus valgus (54%)
clinodactyly V
short metacarpals, IV

Dermatoglyphics

increased total ridge count (mean 166.1)
increased distance between palmar triradii a and b
ulnar loops

The practice of nursing includes diagnosis and treatment of human responses to actual or potential health problems. Among appropriate nursing interventions are identification of health problems, health teaching, health counseling, and providing care supportive to or restorative of life and well-being (ORS 678.010). A logical outcome of this responsibility is for a nurse to identify that girls with Turner's syndrome are at risk for having low self-concept, and to formulate a nursing intervention to deal with this problem. Nurses work with adolescents as individuals and as members of groups. The group approach has been especially successful for dealing with problems of adolescents (Howe, 1980; Rice, 1978).

A number of authorities support the beliefs that adolescents who are different from their peers are at risk for low self-concept; that adolescents respond to treatment in groups; and that self-concept can be improved. However, there is very little empirical evidence available testing strategies to improve self-concept, and virtually nothing in the literature on the use of the group setting to deal with the problems that girls with Turner's syndrome face.

Purpose of the Study

The purpose of this investigation is twofold. The first purpose is to compare the self-concepts of adolescents with Turner's syndrome with those of "normal" adolescents. Secondly, it will test the effects of a specific intervention, group education and counseling, on the self-concepts of adolescents with Turner's syndrome.

Review of the Literature

The following will be considered in the literature review: the

chromosomal basis and somatic and cognitive effects of Turner's syndrome; the nature of self-concept in the adolescent; psychological effects of physical disability on the adolescent; and selected interventions to promote positive self-concept in the disabled adolescent.

Turner's Syndrome

Turner's syndrome is a clinical condition that stems from a chromosomal defect. The occurrence is 1:2500 female births (Riccardi, 1977). The hallmarks of the syndrome are gonadal dysgenesis (with resultant ovarian failure); short stature; and somatic anomalies, any of which may or may not be present in any individual (see table 1) (Simpson, 1975).

The genetic abnormality in Turner's syndrome involves the sex chromosomes in some or all of the cells of an individual. Typically, one sex chromosome is missing and the remaining one is always an X, leaving a total of only 45 chromosomes, or 45,X0. Structural variations of the X chromosome, or XX/X0 mosaicism will also produce the disorder (Gardner, 1975).

The amount and location of genetic material missing from the second X chromosome or, in the case of mosaics, the relative proportions of cell lines with no or an abnormal second X present, roughly correlates with the variation in phenotype seen in the disorder (Ferguson-Smith, 1965). Simpson (1976) has also observed a phenotypic-karyotypic correlation.

Simpson's conclusion is that there are gonadal determinants present on both the short arm (Xp) and the long arm (Xq) of the X chromosome. More than one determinant could exist on each arm. Duplication of one arm (i.e., an isochromosome) does not compensate for the

loss of the other arm; thus gonadal determinants on Xp and Xq must have different functions, each essential for normal ovarian development.

45,X0 is the chromosome complement most frequently associated with gonadal dysgenesis. The proportion of 45,X0 individuals in a given sample will depend upon the method of ascertainment. Jacobs (1972) reports an incidence of 45,X0 newborns as about 1:8000 females. Perhaps 50% of patients with gonadal dysgenesis have a 45,X0 chromosome complement; about 25% have sex chromosomal mosaicism without rearrangements, usually 45,X/46,XX; the remainder have X rearrangements. The most frequent in this group of X-structural rearrangements is an isochromosome for the X long arm, specifically 45X/46,X,i(Xq) mosaicism. Deletions of the long arm (Xq-) or of the short arm (Xp-) are less common; however, each probably occurs more frequently than ring chromosomes, isochromosomes for the short arm (iso Xp), pericentric inversions, X-autosome translocations, or X-X translocations (Simpson, 1976).

Cosmetically, the most conspicuous disfigurements stem from webbing of the neck and a receding mandible. It appears, however, that the cosmetic disfigurements are a less overt concern than short stature, ovarian failure (with lack of pubertal development), and sterility, which are almost universally present in the syndrome (Watson & Money, 1975).

The ovaries look like streaks of connective tissue instead of the normal round shape. They produce neither eggs nor female sex hormones. The affected person will therefore be sterile and will remain sexually infantile in appearance until treated with female sex hormones (Money, 1968). Some girls however, will have transient

residual function of the ovaries with development of some secondary sex characteristics, including menstrual periods.

Gardner (1975) outlined the course of treatment for the short stature and sexual immaturity. Therapy includes two phases: administration of androgens to enhance growth, followed by administration of estrogens to promote development of female secondary sex characteristics. Synthetic androgenic hormones are administered beginning at about 10-11 years of age. This therapy is initiated after x-rays for osseous maturation have been obtained, a careful physical examination has been done, and the therapeutic plan has been explained to the patient and her parents. This treatment lasts for 2-3 years. Eventually, patients are placed on cyclic estrogen and progesterone therapy with resultant menstrual periods. Estrogen therapy promotes development of breasts, labia minora, vagina, and uterus. Estrogen also causes closure of the epiphyses of the long bones, thus making further linear growth impossible. The psychologic effect of delaying feminization must be balanced against the potential for increased linear growth. Even with androgenic hormone therapy, adult height of more than five feet is rare and may be as short as 4.5 feet. Generally it is advisable to avoid undue delay of the institution of estrogen therapy so that girls with gonadal dysgenesis will undergo secondary sexual development near the same time as their peer group. Delay causes the individual to experience unnecessary anxiety and increases the psychologic problems associated with concerns about body image and concept of self.

In addition to the physical abnormalities associated with Turner's syndrome, some other effects have been described. Problems with di-

rectional sense and motor clumsiness, as well as a personality feature termed inertia of emotional arousal have been described by Watson and Money (1975). Inertia of emotional arousal is marked by complacency, stolidity, and slowness in asserting initiative. Individuals with Turner's syndrome have been shown to have space-form blindness (Money & Alexander, 1966), an unusual cognitive defect characterized by an inability to appreciate the shapes and relationships of objects to one another. This defect may explain their common difficulty with numbers.

In addition to physical and cognitive effects, Turner's syndrome may also affect personality. In 1963, Shaffer demonstrated that girls with Turner's syndrome achieved more feminine scores than the average on the Masculine-Feminine scale of the MMPI. These girls have been observed to be markedly maternal in their play and childcare interests from early childhood.

Most people with Turner's syndrome have normal intelligence, but any given 45,X0 patient probably has a slightly higher probability of being mentally retarded than a 46,XX individual. Performance I.Q. is lower than the verbal I.Q., probably due to their space-form blindness (Simpson, 1976).

These physical and cognitive anomalies do make girls with Turner's syndrome different from their peers. This difference may be a problem which will make their adolescence more difficult.

Adolescence

In 1948, Havighurst described his developmental task concept, in which living and growing and learning are processes. Developmental tasks take on the nature of both individual need and social demand in that they arise from the combination of physical maturation, cul-

tural pressures, and the desires and goals of the individual. "They are the things a person must learn if he is to be judged and to judge himself to be a reasonably happy and successful person" (Havighurst, 1974, p. 2). Havighurst lists the developmental tasks of adolescence, the period from 12-18 years of age, as follows:

1. achieving new and more mature relationships with age mates of both sexes
2. achieving a masculine or feminine social role
3. accepting one's physique and using one's body effectively
4. achieving emotional independence from parents and other adults
5. achieving assurance of economic independence
6. selection of an occupation and preparing for it
7. preparing for marriage and family life
8. developing intellectual skills and concepts necessary for civic competence
9. desiring and achieving socially responsible behavior
10. acquiring a set of values and an ethical system as a guide to behavior

An understanding of human development is basic for designing nursing care. The objective of development-oriented nursing care is to enable persons to operate as near their optimum capacity as possible. The science of human development in a sense describes capacity and in addition, identifies people's major methods of functioning and the major hazards to reaching capacity. (Howe, 1980).

Although all the tasks identified by Havighurst are appropriate to adolescents, the girl with Turner's syndrome has special obstacles

to the achievement of Havighurst's first three developmental tasks. The first developmental task, that of achieving more mature relationships with age mates, is made difficult by the short stature and late onset of puberty which tend to separate these girls from their peers. People often treat them according to their height age rather than their chronological age. They are often treated as though they were socially immature (Money, 1976). Turner's syndrome can interfere in several ways with peer relationships and hence with attainment of this task. The young adolescent who feels different may withdraw from peers because comparisons are painful or because of perceived or actual inability to participate as an equal in their activities. On the other hand, an ill or handicapped young adolescent who does not seek peer alliances may be isolated by age mates who, as is typical of adolescents, reject persons whose qualities threaten their own unstable sense of identity and self-regard (Howe, 1980). Delay in accomplishing this developmental task is not likely to have serious permanent consequences, though it may mean a relatively unhappy adolescence. Actual failure in achieving this task means an unhappy adult life. Not only may marriage be difficult, impossible, or unhappy, but these individuals have also failed to learn to work with other people as equals, and in their relationships with people are limited to childish dependence or to arbitrary dominance (Havighurst, 1974).

The second task is to achieve a feminine social role. Despite apparent maternal interests from childhood, girls with Turner's syndrome are virtually always sterile. Sterility, especially when it is untreatable and the diagnosis is final, can deal a devastating blow to the self esteem (Eisner, 1963; Wiehe, 1976). It may also hinder

the achievement of a socially approved adult feminine social role. Havighurst (1974) states that to help girls think through their choices with respect to the feminine sex role, they should be given the opportunity, individually or in groups, to discuss their problems. Women who have been successful in the traditional feminine role of wife and mother should be available to lead such discussions, as well as women who have been successful in other accepted feminine roles.

The goal of the third task, that of accepting one's physique and using the body effectively, is to become proud, or at least tolerant of one's body; to use and protect one's body effectively and with personal satisfaction (Havighurst, 1974). Due to the physical stigmata and short stature accompanying the disorder, the girl with Turner's syndrome has more than the usual obstacles to the achievement of this task. Lerner, Orlos, and Knapp (1976) studied the relationship between adolescents' perceptions of their attractiveness and their self-concept. They demonstrated that attractiveness attitudes contribute significantly to the self-concept of females. Body size and physical height have also been shown to positively correlate with body acceptance and self-esteem (Lechelt, 1976; Wylie, 1974). Secord and Jourard (1953) developed a scale to measure body acceptance (The Body Cathexis Scale) and supported their hypothesis that evaluation of the body and the self tend to be commensurate.

Self-Concept

The terms self-concept and self-esteem are frequently confused. Self-concept may be defined as conscious, cognitive perception and evaluation by individuals of themselves (Zahran, 1967). Self-esteem is a matter of positive self regard (Rice, 1978).

Adolescents are keenly concerned with self-concept. They may ask

"What am I like?" "How good am I?" "What should I or might I become?" "On what basis shall I judge myself?" (Rosenberg, 1965, p. 3). Wright (1960) describes the self picture as an intricate one, made up of the variety of personal characteristics that define for people their psychological identities. Self-concept begins with the development of a notion about one's own body; the satisfactions it provides and denies. Adolescents discover personal interests and abilities, likes and dislikes. They learn something of the way they affect others, being likable or resented, for example. All these perceptions and evaluations make up that separate entity of self in the individual's world.

An adequate self-concept and self-esteem are important to adolescents. Mental health is affected by self-concept (Rice, 1978). Adolescents with low self-esteem are overly vulnerable to criticism, rejection, or to any evidence in their daily lives that testifies to their inadequacy, incompetence, or worthlessness. They may be deeply disturbed when laughed at, scolded, blamed, or when others have a poor opinion of them. The more vulnerable they feel themselves to be, the higher their anxiety levels. As a result, they feel awkward and uneasy in social situations and avoid embarrassment whenever they can.

Zahran (1971) described how interpersonal competence and social adjustments can suffer from inadequate self-concept. One of the unfortunate results for those with poor self-concepts is that they are more often rejected by other people. Acceptance of others, acceptance by others, and acceptance by best friends are related to self-concept scores, with highest acceptance in a group with moderate self-concept scores and lowest in a group with low self-concept scores. Thus,

acceptance of self is positively and significantly correlated with acceptance of, and by, others. Therefore, there is a close relationship between self acceptance and social adjustment.

Self-concept can also affect vocational aspirations. Rosenberg (1965) found a difference in the type of positions desired by adolescents with low and high self-esteem. His findings were, in general, that adolescents with low self-esteem wanted to avoid positions where they will be forced to exercise leadership, and they wanted to avoid where others dominate them. They preferred to be neither power-wielders nor power-subjects. Avoiding leadership or supervision by others is a way of avoiding criticism or judgement. Rosenberg summed up the occupational predicament of the low self-esteem person as follows: "The very thing that makes him so strongly desire success, viz, his low self-esteem, also makes him anticipate failure and very likely helps to produce such failure" (1965, p. 239).

Rathus and Siegel (1973) found a close relationship between delinquency and self-concept. In their study, delinquent youths tended to show lower self-esteem than did nondelinquent youths. According to Rathus and Siegel, an adequate self-concept protects the adolescent from delinquency, because if they see themselves as "good people" or as "nondelinquents," they have developed an inner containment against becoming delinquent.

Our culture promulgates the myth that if a person does not conform to the "norm" then that person is less human or less worthy as a result (Vargo, 1978). Ideas and feelings about the self develop largely as a result of interaction with others, a significant principle for a girl who is different from her peers (Erikson, 1966).

Disability

Wright (1960) proposed that knowledge about the self is built up through sensory experience and through the viewpoints of others, as well as through inferences based on these sources, which makes it possible for the body to become invested with significance beyond its concretely appraised functions. Thus, infertility, short stature, or a webbed neck could be perceived as disabilities, especially as a result of peer disgust or rejection.

A crucial step in adjusting to disability is the triumph over feelings of shame and inferiority (and thus low self-concept). When ideas supporting disability as a sign of personal inferiority are eliminated, the process of adjustment is facilitated. Wright identified ten ideas commonly held by those who are disabled which tend to support the concept of disability as a sign of inferiority (1960, p. 172):

1. My disability is a punishment.
2. It is important to conform, not to be different.
3. Most people are physically normal.
4. Normal physique is one of the most important values.
5. Physique is important for personal evaluation.
6. A deformed body leads to a deformed mind.
7. No one will marry me.
8. I will be a burden on my family.
9. My deformity is revolting.
10. I am less valuable because I can't get around (or see, or hear) as others can.

Some of these can be discarded or at least weakened through fact-

ual and scientific knowledge. Others require basic changes in one's value system or outlook on life.

The development of a positive self-concept is an important task for the adolescent. A negative self-concept may contribute to several types of personal and interpersonal problems. The somatic anomalies associated with Turner's syndrome are a special obstacle to the achievement of a positive self-concept.

Interventions to Promote Positive Self-Concept

The Group Approach. The group setting is advocated by Reinherz (1976) as an effective tool for enhancing adolescent self-concept. His report on the work of a Massachusetts community counseling center for adolescents revealed that it was possible through psychotherapy and group activity to significantly raise the self-esteem scores of about half the troubled adolescents ages 14-23 who came to the center. These youths had difficulties at work, school, and with friends and parents. Some form of drugs were used by 81%. Interviews following group sessions showed many youths had developed more self-confidence after treatment enabling them to drop harmful friendships and initiate new relationships. They reported better relationships at work, school, and with parents. Many showed a decrease in drug use. The important point is, the self images and lives of many of these adolescents were changed, with difficulty, but nevertheless with positive results.

Howe (1980) found that a benefit of the use of groups when dealing with adolescents is that they will group members and provide support for one another for self-confidence, self acceptance, social acceptance, independent functioning, and coping. Many adolescents

benefit enormously from meeting others who share their particular health problem.

Although there are virtually no precedents in the literature for dealing with adolescent Turner's syndrome patients, groups have been used for adolescents with other health problems. Sullivan (1979) studied 105 adolescent diabetic girls and found adjustment in peer group relationships to be directly related to self-esteem (the Rosenberg Self-Esteem Scale was used). She also saw positive benefit for these girls in seeing that other girls have diabetes too. After group therapy, individuals with hemophilia have been shown to have heightened personal awareness, self satisfaction, and positive feelings as measured on the Tennessee Self-Concept Scale (Caldwell, Leveque, & Lane, 1974).

A group of similarly affected adolescents can be uniquely supportive to the young person grappling with illness or disability and, at the same time, with developmental tasks. Both techniques and attitudes to facilitate coping and promote task mastery can be obtained from fellow patients who have firsthand experience in being an adolescent with a health problem, especially if it is the same health problem. Adolescents often identify with and trust peers in ways they are unable to do with adults, including health professionals (Howe, 1980).

In a comparison of outcomes of individual and group counseling with ninth grade girls, Wearne and Powell (1976) found the group counseled subjects to have experienced more favorable changes in self criticism, identity, moral-ethical self, family self, and orientation to school. Another advocate of group over individual counseling is

Bennett (1963) who listed five reasons for the superiority of the group approach:

1. The group provides a more realistic life situation than an individual counseling session in that an individual can engage in reality testing with other members. The group provides a lifelike situation in which interpersonal relationships can be examined and new techniques of relating to others can be tried out in a protected environment in which learning can result from both failures and successes without undue traumatic aftereffects.

2. The group experience is almost certain to reveal many common problems. Communication in the group tends to accentuate the universal and the commonplace in human experience. Recognition of the common nature of problems tends to decrease tension and anxiety about one's own situation.

3. The bond of common concerns fosters an altruistic desire to help one another, so that the therapeutic service is extended beyond the therapist to include the group.

4. An intimate, cohesive group tends to resemble a primary family group in which many common themes will be explored: first relationships with parents and sibs; next with peers and with authority figures. It may tend to relieve a feeling of loneliness and isolation.

5. Mutual acceptance, affection, respect, and helpfulness within the group tend to develop improved self-concepts and act as a force toward normalcy.

Thus the group approach is an important one for dealing with the adolescent. Also important to the adolescent is the provision of honest information. There is general agreement regarding the necessity of giving honest, accurate information. Howe, (1980) described

honesty as an indispensable part of the interventions used to help an adolescent deal with disability. Adolescents, because of their age-typical idealism and tendency to view things as either all one way or all another, may feel that an adult who hedges about the truth in even some minor matter is a liar and subsequently not a reliable source of help.

Beare (1975) included both counseling and honesty among his four steps for enhancing the self-concept of adolescents:

(a) reconditioning through repeated successes in the area of difficulty for the adolescent; (b) input of accurate information about the self; (c) integration of such information through counseling; and (d) altering the parents' concept of the adolescent.

Money (1978) advocates complete honesty about the infertility associated with Turner's syndrome, but recommends that the patient be counseled to achieve parenthood through adoption. This leaves the idea of parenthood intact, altering only the way it is to be achieved.

Education. Education, or information sharing, is supported in the literature as a method of enhancing self-concept and promoting independence. Huckaby (1976) demonstrated a positive relationship between sense of academic achievement and acquisition of knowledge, and an increase in positive self-concept.

Howe (1980) lists four benefits to being informed about one's medical situation: (a) ability to participate in the care regime as co-planner and partner in conducting and evaluating interventions; (b) development of a sense of responsibility for self that will help ensure responsible self-care in the future; (c) development of self-esteem based on the knowledge that one has the confidence and respect

of one's health care professionals, and; (d) avoidance of unnecessary mistakes that can easily occur when the naturally self-asserting adolescent takes action that is not based on sufficient information.

It is particularly important for girls with Turner's to understand the nature and function of hormones in the human body. Such knowledge will assist them in decision making about their treatment. There is a point at which affected individuals, with their parents, will have to make the choice between continuation of androgen therapy for increased linear growth and the initiation of estrogen therapy. The latter therapy will induce puberty as well as closure of the epiphyses of the long bones (Johanson, Brasel, & Blizzard, 1969).

Carl Rogers (1951) agreed that education is a tool for enhancing self-concept, but contended that teaching should be student-centered. He viewed student-centered teaching as essentially client-centered therapy applied to the classroom. He hypothesized that student-centered teaching should result in changes in self-concept similar to those seen in client-centered therapy, that is self-concept should change, approximating the ideal self-concept.

Summary

Turner's syndrome is a clinical condition which stems from a chromosomal abnormality. Physical findings include gonadal dysgenesis, short stature, and somatic anomalies. These abnormalities may make it more difficult for girls with Turner's syndrome to accomplish some of the developmental tasks of adolescence, such as: achieving new and more mature relationships with age mates; achieving a feminine social role; and accepting one's physique and using one's body effectively.

The literature supports the hypothesis that adolescents who are different from their peers are at risk for having negative self-concepts. There are also reports in the literature demonstrating that self-concept can be improved.

Group counseling and education have been proposed as effective tools for dealing with adolescents. Although no references have been made to the use of these intervention strategies with Turner's syndrome patients, girls with Turner's syndrome are assumed to have similar concerns to other dysmorphic adolescents.

CHAPTER II

Methods

The research questions to be considered by this study include: To what extent does the self-concept of adolescent girls with Turner's syndrome differ from the self-concept of "normal" girls in the same age group? and; To what extent can group education and counseling improve the self-concept of adolescents with Turner's syndrome?

Design

A non-equivalent control group pretest-posttest quasi-experimental design was used. Because the participation of the entire population of individuals meeting the study criteria was requested, no randomization was done. The pretest of the Piers-Harris Children's Self-Concept Scale (see Appendix B) was administered to members of the experimental group individually in their homes during an interview with the investigator. The posttest was given after the experimental intervention (a series of four education and counseling sessions) was complete. The tests were administered to the comparison (control) group by mail, the posttest four weeks after the pretest.

Sample

The population was defined as all individuals with cytogenetically confirmed Turner's syndrome, ages 13-18, living within a one hour's drive of the University of Oregon Health Sciences Center. This age group was chosen because it was anticipated that the girls would benefit most from education and counseling early in their course of estrogen therapy. Names and diagnoses of affected girls were obtained from a pediatric endocrinologist practicing at the University of Oregon Health Sciences Center who evaluates and treats most of the

Turner's syndrome patients in Oregon. Ten girls met the study criteria.

The nurse investigator contacted the parents of each of the ten potential subjects to explain the study and to request their participation. Four parents were interested, and consented to meet with the investigator in their homes. A personal interview with each subject and her parents was requested in order to give the families an opportunity to meet the investigator, and to have their questions about the study answered. This opportunity was also taken to have consent forms signed, to administer pretest questionnaires, to collect demographic data, and to gather descriptive data regarding the circumstances surrounding the diagnosis of Turner's syndrome in each family. At this initial interview, these four girls agreed to be a part of the study, and became the experimental group. Three of the original ten mothers refused to be involved, and their daughters were never contacted. Of the three families who chose not to participate in the study, one mother refused to allow her daughter to be a part of the study because she did not want her daughter to find out about her infertility yet. Another mother declined because she does not perceive her daughter as different, and does not want the daughter to feel that she is not like her peers. Still another mother, whose daughter is an XO/XY mosaic, chose not to be a part of the group because she did not want her daughter to be subjected to further anxiety by being reminded of the recommendation for surgery to remove gonadal tissue (there is a risk for gonadoblastoma when these girls have an XY cell line). The remaining three families were interested, but because of prior commitments of their time, were unable to attend the

group sessions. These three girls did agree to answer the questionnaires, and became a part of the control or comparison group. Three other girls, who were not included in the original population of ten because they live too far away from the Health Sciences Center to attend the meetings, also consented to join the comparison group. These last three girls met the criteria for age and diagnosis also.

Dependent Variable: Self-Concept

Self-concept was measured by the Piers-Harris Children's Self-Concept Scale, and for the purposes of this study, the degree of positive self-concept was defined as the score on that scale. This measurement tool was chosen because it was developed especially for the use with children. Its items cover several factors of self-concept, particularly physical aspects, abilities, and personality, which are relevant concerns to individuals with Turner's syndrome. The Piers-Harris scale is in wide use and has been standardized on children in grades three through ten.

The scale consists of 80 items, relating to six aspects of self-concept. The items are clearly written, and require a yes-no response. They tend to be declarative statements, thus avoiding double negatives, and contributing to clarity (Crandall, 1973). Six factors of self-concept are measured: 1) behavior; 2) intellectual and school status; 3) physical appearance and attributes; 4) anxiety; 5) popularity; and 6) happiness and satisfaction.

Scoring. Items are scored in the direction of high self-concept, with a maximum possible score of 80, and a minimum of 0. Because no consistent sex or age differences have been found, the scores of 1183 public children were pooled for normative purposes (Piers & Harris,

1969). The means by grade level for this sample have been presented separately (see Appendix D). It is this group of 1183 children who will serve as the normative sample for this study. Average scores are usually considered to be those between the 31st and 70th percentiles, or between the raw scores of 46 and 60.

The mean of the normative sample is 51.84, and the standard deviation is 13.87. The median is 53.43. Piers and Harris have observed that as with many personality measures, these measures of central tendency tend to reflect negative skewness, or the tendency of the general population to respond in a generally positive fashion.

Reliability. Internal consistency was tested by Piers and Harris who found alpha coefficients (the average of all split half coefficients) ranging from .78 to .93 (Crandall, 1973). Test-retest reliability was demonstrated by two- and four-month test-retest coefficients of .77 for 244 fifth graders in the Oregon public schools (Piers and Harris, 1969).

Validity. An attempt was made when the scale was developed to build in content validity by defining the universe to be measured as the areas about which children reported qualities they liked or disliked about themselves. Convergent validity is demonstrated by the fact that the scale correlates positively with the Lipsitt self-concept scale (.68) and negatively with anxiety and similar measures (-.48 to -.69), as would be expected.

Other Variables

Demographic data were also collected, including: subject's birth-date, year in school, age at time of initiation of estrogen therapy, number of siblings, birth order, and age when diagnosis of Turner's

syndrome was made. Each individual was also asked to indicate two possible future career choices, in an attempt to substantiate Shaffer's (1963) finding that individuals with Turner's syndrome are especially maternally oriented. After parental and individual consents were obtained, physical findings pertinent to Turner's syndrome were obtained from their medical records. A data Collection Sheet (see Appendix E) was kept for each subject, and was identified by code number. The demographic and career choice information, as well as attendance records for the group meetings were kept on these sheets.

Intervention: Education and Counseling Sessions

The experimental intervention was exposure to a series of group education and counseling sessions. There were four two-hour group sessions, held one evening per week. A portion of each session was a didactic presentation conducted by a speaker expert in the area of focus. The four major topics covered in the didactic presentations were: 1) the genetic basis of Turner's syndrome, including common physical findings; 2) the endocrinological aspects, and hormone therapy; 3) growing up with Turner's syndrome, and vocational planning; and 4) social concerns and interpersonal relationships. This part of each meeting was attended by subjects and interested parents.

Following the educational presentation, subjects and parents were separated. The rationale for the separation was that the girls may have been able to express themselves more freely apart from their parents. The subjects participated in a group counseling activity conducted by the investigator and a sex educator who does adolescent group counseling for the Crippled Childrens Division. The tasks of the counseling portion were: answering the girls' questions, discuss-

sion of common concerns, facilitation of interaction between the girls, and conducting self-esteem enhancing exercises. The parents, who were not a part of the study, were involved in a discussion group moderated by a Clinical Nurse Specialist, who is an expert in parent group therapy.

The following summary describes significant aspects of each of the education and counseling sessions.

Session 1. The speaker at the first didactic session was the investigator. The chromosomal basis of Turner's syndrome was the topic of discussion. Formation of the abnormal zygote, etiology, incidence of the disorder, and common physical findings were discussed. The subjects and their parents were particularly interested in information about recurrence risk, space-form blindness, the selective advantage of Turner's syndrome fetuses which survive to term, frequency of occurrence, and the risk of mental retardation. One subject related that she had been told in school that people with chromosome abnormalities such as Turner's and Down's syndromes, are mentally retarded.

The presentation of common physical findings prompted a comparison of stigmata during the counseling portion of the meeting. The girls compared their necks, hands, and heights. Being short was a major subject of discussion. The girls described positive and negative aspects. On the positive side, small people can fit into small places, people are protective of short people, and maybe boys like girls to be shorter than they are. On the negative side, it is hard to reach things (like kitchen cupboards), short people are often treated as though they were younger than they really are, sometimes short people are discriminated against (one girl was cut from the volleyball team,

even though she had comparable skill, because she was the shortest player), and fitting clothes can be difficult. They had all shared the experience of needing to cut several inches from the length of the shortest pants they could buy.

The "Feeling Good" card game, which was designed as a self-esteem enhancing exercise was played. Each of the "Feeling Good" cards asks a question or requests a statement from the player, eliciting responses which disclose feelings and attitudes or are statements of positive self-concept. The cards are dealt out singly to each player, who in turn responds to the instruction.

Session 2. A pediatric endocrinologist was the speaker at the second session. His topic was the endocrinologic aspects of Turner's syndrome. He presented definitions of terms, the location and function of the endocrine glands, hormone function, puberty, how Turner's syndrome affects the endocrine system, and hormone therapy.

During the pre-study interviews, several girls and their parents stated that they would especially benefit from a review of the endocrinology of Turner's syndrome. Some specific concerns expressed during the question and answer period were: aging in Turner's syndrome (is it accelerated?); what would happen to a Turner's syndrome patient without hormone therapy; hormone dosage (the girls compared which medications they were taking and the dosage); and whether or not estrogen therapy increases the risk of cancer.

The group discussion following this presentation was lively and uninhibited so parents were not separated from the girls' group. A variety of poignant responses stemmed from the question "How did your family react to the diagnosis?" One girl's father and brother

cried. A year later her father is still emotional about it. She was glad that her mother was more accepting. Another family was having so many other problems that they had little energy to deal with a difficulty like Turner's syndrome. This girl ran away from home and now lives with her great aunt who views Turner's syndrome as an affliction which can be overcome with much support and assistance. The mother of one of the girls who was diagnosed early (age 10) related that she was reluctant to talk with her daughter about the diagnosis. She was confused, had unresolved feelings of her own, and did not know what to say to her young daughter. The last girl was also diagnosed early. Her parents said that they privately agonized about what she may have to go through, but were positive and optimistic in her presence.

Session 3. The topics of discussion at the third session were: growing up with Turner's syndrome, and vocational planning. The guest speakers were an adult with Turner's syndrome, and two 18 year olds with Turner's syndrome, who have made their career choices, and will be college freshmen in the fall. The students shared their feelings about having Turner's syndrome, and described the process they used in arriving at their vocational choices. One plans to major in special education at Oregon College of Education. The other will study early childhood education at a private religious college.

The adult with Turner's syndrome was accompanied by her mother, husband, and two adopted children. Her mother described the ordeal of seeking an explanation for her daughter's problems. She went from physician to physician, and state to state, until finally her daughter was the first case of Turner's syndrome diagnosed at the Mayo Clinic

in Minnesota. Two of the subjects' mothers affirmed their identification with her experience. The husband stated that he gives little thought to his wife's Turner's syndrome. According to him, they have a normal and happy family life.

The woman was very positive, urging the girls to accept themselves for what they are, as she has done. She talked about choosing nursing as her career, and having a hospital school of nursing reject her application for admission because of her short stature. She was finally accepted into another school when a physician friend wrote a letter of recommendation stating that she was a capable person despite her height.

The group had an animated discussion comparing their physical characteristics and their reactions to being a little bit different from their peers. Each girl also discussed her feelings about hearing the diagnosis of Turner's syndrome. The reactions were: shock, relief that it was not something more serious, relief to finally have an explanation (or a label) for their problems, and confusion.

Each girl was also asked to comment on her future plans. Themes common to every plan were: marriage, adopting children, and a service-oriented career.

The final topic of discussion was about timing in telling others about having Turner's syndrome. The adult with Turner's syndrome and the girls agreed that this information is of a very personal nature and should not be casually disclosed to acquaintances. The issue of telling a boyfriend was particularly sensitive. No consensus could be reached.

Session 4. The final session was conducted by the sex educator who was group co-leader. A value's game was used as a background for

the session's major focus on interpersonal relationships. In this game each player prioritizes a list of values and characteristics according to their desirability in a future spouse or partner, and then explains their rationale. The list of values included: intelligence, self respect, respecting others, sense of humor, good looks, sharing with housework, having a lot of money, having the same interests, liking to touch and hug, being a person you can talk to, having a good job, and one other characteristic of the player's choice. Having self respect and showing respect to others were the most common first choices. Personal qualities took priority over tasks for all players.

The game stimulated further discussion about relationships and dating. The girls heartily agreed that interpersonal relationships with boys can be awkward. None of the girls had gone out on a "date" with a boy alone. They all agreed that there is no special age when a girl should be allowed to date, and that the decision to date is an individual one depending on each girl's maturity. In the discussion of premarital intercourse, the girls made statements such as: "I'm old fashioned." "It's not for me." and "Boys sometimes take advantage of girls." The girls were also invited to comment on being a woman in our society. Traditional roles and values were listed by the girls, and compared to contemporary changes.

Evaluation of Sessions by Subjects

A portion of the final session was reserved for evaluation. The subjects were asked to provide a written, unsigned response to the following four questions:

1. Do you know more about Turner's syndrome now than you did before this study?

All four answered "yes."

2. What was the most positive thing about being a part of this study?

Two cited meeting other girls with Turner's. One most enjoyed meeting the adult with Turner's syndrome, and her positive attitude. One benefitted most from being able to talk with people who really understand how she feels.

3. What was the most negative thing about this study?

One left this answer blank. One said that nothing was negative, and two said it would have been better if more girls had been involved.

4. Did you personally benefit from being part of this group, and if so, how?

One wrote "Yes it was real good. I don't know what else to say." One benefitted most from getting to know others with Turner's syndrome (but did not say how). One commented that the comments of the woman with Turner's syndrome were most helpful, because "it never bothers her." And one wrote "Yes, I think I know myself a little better."

CHAPTER III

Results

The analysis of study findings is presented in the format of answering the questions presented by the study. Case study data is also included in response to the first question.

First Study Question

The first question addressed by this study was: To what extent does the self-concept of adolescents with Turner's syndrome differ from the self-concept of "normal" girls in the same age group? To answer this general question about girls with Turner's syndrome, the initial self-concept data from both experimental and comparison groups were summarized and compared to data obtained by Piers and Harris from their sample of normal subjects (see Table 2). Descriptive data gained through individual interviews with the experimental group was also used.

Piers and Harris consider the average score in their normative group to be between the 31st and 70th percentiles, or between the scores of 46 and 60. The mean of the normative sample is 51.84, with a standard deviation of 13.87. Except for one very high score in the comparison group, all Turner's syndrome girls tested (in both experimental and comparison groups) scored in the average range, or slightly above (see Table 2). As for the very high score (the 99th percentile), Piers and Harris state that such very high scores may be an attempt by the child to answer in response to her perception of how she has been told she should act or feel, and may not reflect truly positive self attitudes. At the time of this study, the self-concept of the subjects with Turner's syndrome did not differ significantly from that of their

Table 2
Self-Concept Scores

subject number	score before study	score after study	amount and direction of change
Experimental Group			
E1			
raw score	58	61	+3
percentile	63	71	+8
E2			
raw score	52	61	+9
percentile	46	71	+25
E3			
raw score	62	70	+8
percentile	74	93	+19
E4			
raw score	63	59	-4
percentile	77	66	-11
Comparison Group			
C1			
raw score	77	76	-1
percentile	99	99	-1
C2			
raw score	62	65	+3
percentile	74	82	+8
C3			
raw score	56	57	+1
percentile	57	60	+3
C4			
raw score	55	58	+3
percentile	55	63	+8
C5			
raw score	58	60	+2
percentile	63	69	+6
C6			
raw score	65	66	+1
percentile	82	85	+3

normal peers (see Table 3).

This finding does not, however, rule out the possibility that having Turner's syndrome may be a threat to a girl's self-concept at some time in her life. Evidence from the case studies suggests that this threat did in fact occur, at least for the four members of the experimental group for whom such data were available. At some time in each of these subject's lives, the reality of having Turner's syndrome had caused appreciable stress and frustration.

Aguilera and Messick (1974) describe crisis as characterized by severe stress, disruption of life routines, acute frustration, and feelings of helplessness. Brammer and Shostrom (1977) state that the most common type of crisis is associated with loss, or impending loss of a loved one, a prized job, health, or physical strength. It may be extrapolated further that the diagnosis of abnormality, such as Turner's syndrome, may be felt as the loss of a girl's perception of herself as perfect, and may precipitate a crisis.

As evidenced by the fact that these girls with Turner's syndrome currently feel as positively about themselves as do their age mates, they may have resolved any crisis that was precipitated by having Turner's syndrome. Factors which may have contributed to crisis resolution for these girls include: individual or family coping mechanisms, information and education about Turner's syndrome given by the genetics clinic, counseling of patient and family by the pediatric endocrinologist at the time of diagnosis, and at subsequent clinic visits, and counseling and support by community resources (family pediatrician, nurse, social worker, clergy).

Another point to be considered is the selection of subjects. Al-

Table 3

Self-Concept Scores of Turner's Syndrome and Normal Subjects

	Turner's Syndrome Girls	Normative Group
	N=10	N=1183
Mean	60.80	51.84
Range	52-70	46-60*
Percentile	46-99	31-70*

*Range and percentile scores represent the average range as described by Piers and Harris (1969) for the normative group.

though the entire population meeting the study criteria was contacted and asked to participate, not all consented to do so. In fact, some of the girls with the greatest needs may have been omitted from the study. It appears from the mothers' reasons for refusing participation (see page 22) that these families may be in a stage of denial about the diagnosis of Turner's syndrome.

The study subjects may have chosen to participate because they have normal self-concepts and are able to take the personal risks of joining a group of strangers. These girls may be more comfortable with the diagnosis of Turner's syndrome as a result of intervention they have already received.

Case Studies

The following are summaries of data gathered during home interviews with each subject in the experimental group and with her mother. Data from individual medical records is also included.

Subject #1. Subject number one was 18 years old at the time of the study. She is the oldest of five children. She had multiple family problems and is now living with her great aunt. A senior in high school, she is two years behind in school (which may be related as much to the family situation as to academic aptitude). Turner's syndrome was diagnosed at age 12. She was referred for evaluation because of short stature (she is less than the fifth percentile for her age). Other physical findings associated with Turner's syndrome include: short webbed neck, low posterior hairline, "square" body habitus, and a grade II/VI systolic murmur. Chromosomal analysis showed 45,X0: classic Turner's syndrome.

At first she ignored the diagnosis of Turner's syndrome because

she did not understand it, but now she is relieved to have an explanation for her short stature, low hairline, and trouble with mathematics. She was once fired from a job at a fast food restaurant because she was too short to reach the necessary shelves. Speech and hearing therapy is her first career choice. As a second choice she wants to work with children in some capacity.

Subject #2. Subject number two was 14 years old at the time of the study, and in the ninth grade. She is the second of three children. Her mother was concerned about her "slow growth" and took her to several pediatricians (and relates that she was called "hysterical" and "over-protective") before the diagnosis of Turner's syndrome was made at age 10. This subject was not initially concerned about the diagnosis and told a few close girlfriends about it. As the months passed, and she thought more about it, she became very anxious about having anyone know about her diagnosis, especially the infertility, because "they didn't really understand it." She was very relieved when her family moved to another school district the next year. She has not told any of her new friends.

Physical findings include: height less than the fifth percentile for her age, pigmented nevi, stocky build, epicanthal folds, grade I/VI systolic murmur, mild hypertension, shield shaped chest, ulnar loops on all fingers and thumbs, frequent ear infections, and chronic lymphocytic thyroiditis. Cytogenetic analysis shows 45,X0. She began estrogen therapy at age 14. Her career choices are social worker and dietician.

Subject #3. The third subject was 18 years old and a senior in high school during the study period. She is the second of three child-

ren. She and her mother suspected that something was wrong earlier but finally saw the pediatric endocrinologist at age 17 for primary amenorrhea. Her father cried upon hearing the diagnosis, and is still "very emotional" about it.

She is short, has a short neck, short fingers, and a stocky build. Her chromosomes are 45,X0. This subject has always had trouble with mathematics in school, although she reads very well. Her family is very athletic but she describes herself as "clumsy." She has space-form blindness (although she did not know the term for this disorder before the study) and has difficulty driving a car and following a map or directions.

Now that she is accustomed to the idea ("It was hard to take at first.), having Turner's syndrome is "better than a lot of things I might have had." She loves children and plans on parenthood through adoption when she is ready. Her career choices are: special education and elementary education.

Subject #4. The fourth subject is an only child who was adopted in infancy. She was originally referred for short stature at the age of 10. It was then that the diagnosis of Turner's syndrome was made. She was 14 years old at the time of the study, and in the ninth grade.

Her chromosomal complement is 45,X0. She is short, has a short neck, stocky build, and has multiple pigmented nevi. She does very well in school. In contrast to some of the other subjects, she does especially well in mathematics. Subject and mother both described feeling very confused when the diagnosis of Turner's syndrome was made, but both feel relieved now that they know more about it. Social work and teaching are her career choices.

Observations and Anecdotes

A common theme emerging from the interviews was that each girl has, at one time or another, experienced a crisis associated with her Turner's syndrome. For some the crisis involved the frustration of undiagnosed abnormality. One member of the comparison group told the investigator that she cried every night after school because she did so poorly in arithmetic. Her little brother could do her homework, but she could not. She was put into classes for slow learners, even though she was a good reader, and mathematics was her only difficulty. She described herself as "plain, fat little K---." Her mother took her to several physicians, none of whom had any answers. The mother was accused of trying to "rush her daughter into puberty," and told to "just relax, she'll grow." When Turner's syndrome was finally diagnosed at age 15, both mother and daughter were relieved. They were very happy to have a label for what was wrong with K---. She was particularly happy to know that it was not really her "fault" that she had trouble with mathematics. Estrogen therapy was very successful in inducing puberty. Even her classmates remarked that she was "blooming." By the time the investigator reached her, the crisis was resolved.

For others, the crisis occurred with the diagnosis. These girls and their families had suspected that something was wrong and sought medical assistance, but were not prepared for the prospect of life-long drug therapy, short stature, and sterility. The pediatric endocrinologist was instrumental in resolving crises for this group of girls. After the diagnosis of Turner's syndrome was made, he informed each girl and her family about the disorder and its implications. He has also seen them in the genetics clinic on a regular basis.

In all situations, a crisis evolved, whether out of the adolescents' perception of herself as different or abnormal, or from the diagnosis itself. It appears from the results of testing with the self-concept scale that these crises were resolved by the time the study was conducted.

Second Study Question

The second study question was: To what extent can group education and counseling improve the self-concept of adolescents with Turner's syndrome?

This question was answered by comparing the changes in self-concept scores of the experimental group with those of the comparison group.

Pretest scores on the Piers Harris Scale in the study group ranged from 52 to 63 with a mean of 58.75. The pretest mean of the comparison group was 62.17 (see Table 4). If the one artificially high score (77 or 99th percentile) in the comparison group were omitted, the mean would be 59.2, virtually the same as the pretest mean of the experimental group.

Posttest scores in the study group ranged from 59-70. The posttest mean was 62.75. The comparison group had a posttest mean of 63.67, or 61.2 if the high score was omitted.

Changes in the experimental group ranged from -4 to +9, with a mean change of +4 (see Table 2). The subject with the lowest self-concept at the outset had the greatest positive change. The only negative change was in the subject who initially had the highest score. One explanation for a negative change in self-concept is that a subject could take a more critical look at herself after discussing her

Table 4
 Self-Concept Scores Before and After
 Experimental Intervention

	Experimental Group*	Comparison Group**
	N=4	N=6
Mean		
pretest	58.75	62.17
posttest	62.75	63.67
Range		
pretest	52-63	55-77
posttest	59-70	57-76
Percentile		
pretest	46-77	55-99
posttest	66-93	60-99

*Four girls with Turner's syndrome who participated in counseling sessions.

**Six girls with Turner's syndrome who served as controls.

abnormalities with a group such as this one. This is unlikely, however. In this case, the negative change is more likely due to an inconsistency on the part of the subject in the way she responded to the questionnaire. For example, on the pretest she answered "yes" to the statement "I am good in music" and "no" to "I get nervous when the teacher calls on me." She changed both answers on the posttest. It is unlikely that her musical ability or school anxiety changed over the four-week test period. In the comparison group, changes in score ranged from -1 to +3, with a mean change of +1.5. The mean change in the experimental group exceeded that of the comparison by 2.5.

For interpretation of individual scores on the Piers Harris Scale, the standard error of the mean was employed. Piers and Harris found the average of the standard deviations over several samples at different grade levels to be approximately 13. The SE_m would thus be approximately six points (Piers, E. V. and Harris, D. B., 1969, p. 5). A difference significant at the .05 level would require a change of almost twice the SE_m . The developers of the scale recommend, therefore, that individual changes in score of less than 10 points be ignored.

The change in test scores was in the expected direction, but was small. None of the scores, either in the study or comparison groups, changed by 10 or more points (see Table 3). Thus, there was no significant change in the self-concept of the subjects after exposure to the experimental intervention.

Because the study group was not initially low in self-concept as originally predicted, the potential for significant change did not exist. At the time this study was conducted, the subjects did not need help on improving their self-concepts. A possible explanation

for this finding is that the four girls who consented to participate in the study may have done so because they had the greatest self-concept at the outset. They may also have benefitted from intervention before the study. There may also be other variables influencing self-concept not identified by this investigation.

The group approach to counseling was chosen for use in this study because the reports in the literature support it as beneficial for use with adolescents. Bennett (1963) identified five advantages to group counseling:

1. The group provides a more realistic life situation than an individual counseling session in that an individual can engage in reality testing with other members.
2. The group experience is almost certain to reveal many common problems. Communication in the group tends to accentuate the universal and the commonplace in human experience. Recognition of the common nature of problems tends to decrease tension and anxiety about one's own situation.
3. The bond of common concerns fosters an altruistic desire to help one another, so that the therapeutic service is extended beyond the therapist to include the group.
4. An intimate, cohesive group tends to resemble a primary family group in which many common themes will be explored: first relationships with parents and sibs; next with peers and authority figures. It may tend to relieve a feeling of loneliness and isolation.
5. Mutual acceptance, affection, respect, and helpfulness within the group tend to develop improved self-concepts and act as a force toward normalcy.

Most of his predicted benefits were realized by this study group

as part of the group process. Secondly, the counseling sessions were very successful at promoting communication about common problems. Thirdly, their desire to help one another was expressed in their suggestions they gave each other about how to deal with the common frustrations of Turner's syndrome, such as remembering daily medication, and reaching the pedals in the car.

Bennetts fourth statement, that an intimate group will explore many common themes, such as relationships with parents and sibs, and peers and authority figures also held true. The girls did discuss relationships. Several commented that as a result of this group participation they do not feel as isolated or as unique as they did before.

Contrary to his fifth prediction, no significant improvement in self-concept was made.

As evidenced by their spontaneous comments, the subjects gained subjective benefit from group participation. The subjects cited the following benefits:

1. their first opportunity to meet other girls with Turner's syndrome
2. the opportunity to interact and identify with girls of their own age who share their feelings and experiences
3. the opportunity to meet and learn from an adult who has successfully dealt with the challenges of Turner's syndrome
4. the opportunity to learn more about the genetic and endocrinologic aspects of Turner's syndrome

Because of the small sample size, it was inappropriate to analyze the demographic data for meaningful trends. It is interesting, however, that all of the girls have chosen service oriented careers (ed-

ucation and social work were popular). It is difficult to cite a maternal personality trait as the impetus behind the choices. A similar group of girls who do not have Turner's syndrome may have responded in the same way.

CHAPTER IV

Summary Conclusions and RecommendationsSummary

The purpose of this study was to ascertain whether adolescents with Turner's syndrome have a lower self-concept than their "normal" peers, and if they do, to determine to what extent group education and counseling can improve their self-concepts. The self-concept of four girls in the experimental group and six in the comparison group was measured by the Piers-Harris Children's Self-Concept Scale. The scores for both groups were within the average range. The four subjects in the experimental group were then involved in a series of four group education and counseling sessions. The posttest questionnaires indicated a tendency for self-concept scores to be more positive, without statistical significance. Although the major need of these girls at the time of the study was not in the area of self-concept, it does appear that they gained subjective benefit from participation in the study group. Subjects stated that they benefitted especially from the opportunity to interact and identify with other similarly affected girls, to meet and learn from an adult with Turner's syndrome, and to learn more about the genetics and endocrinology of Turner's syndrome.

Conclusions

The sample size in this study was not limited by time or practical considerations, but by the population itself, due to the fact that Turner's syndrome is a relatively unusual disorder. The limitations imposed by the small sample size and non-randomization make it difficult to draw strong conclusions or generalizations. The following conclusions refer to the study population.

1. The ten subjects with Turner's syndrome who participated in this study had self-concepts within the average range of their "normal" age mates. It is important to note that although the subjects were adolescents who were different from their peers, they did not have negative self-concepts. Therefore, it cannot be assumed that adolescents will adapt negatively to the diagnosis of Turner's syndrome.

2. The experimental group education and counseling sessions did not significantly improve the self-concepts of the study group members, as they were measured by the Piers-Harris Children's Self-Concept Scale.

3. Members of the experimental group experienced a crisis associated with their Turner's syndrome, which had been resolved by the time they participated in the study.

4. Participation in the group education and counseling sessions was beneficial to the subjects involved in ways not measured by the study.

Recommendations for Practice

1. An attempt should be made to reach and support girls and their families as soon as possible after the diagnosis of Turner's syndrome is made.

2. The time of diagnosis of Turner's syndrome can be a stressful event. Developmental events such as dating, choosing a career, marriage, and planning a family, may also be particularly difficult for people with Turner's syndrome. There should be a nurse, physician, or other counselor available to these people to assist them in dealing with these particularly stressful periods.

3. The study group supported reports in the literature that bringing together people with the same diagnosis can be beneficial to them. Nurses, by organizing groups and facilitating the group process,

can benefit group members. This intervention may be especially helpful for people with unusual disorders.

4. Early case finding may save families from the frustration of undiagnosed abnormality in their daughters. Educating physicians, nurse practitioners, and school nurses about Turner's syndrome and the diagnostic and treatment facilities available for Turner's syndrome patients may improve the health care of individuals with Turner's syndrome.

Recommendations for Research

1. Developmental information about self-concept in Turner's syndrome is unavailable. A longitudinal study, possibly by a clinic nurse who has the opportunity to see individuals with Turner's syndrome over an extended period of time, would be valuable in documenting the crises these girls experience, and how self-concept is affected. This would also be an excellent opportunity to assess the effectiveness of nursing intervention to resolve crises or enhance self-concept.

2. Significant improvement in self-concept may require long term intervention. Education and counseling sessions may yield positive results when used with adolescents with low self-concept if conducted on a long term basis.

3. Very little is known about adults with Turner's syndrome. By identifying and studying the health behavior (such as whether they take estrogen and have yearly pap smears) of these women, a nurse may be able to identify their needs and improve their health care.

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APPENDICES

APPENDIX A

Consent Form for Human Research

Informed Consent and Authorization for Release of Information

I, _____ agree to be a part of a study called "The Effect of Group Education and Counseling on the Self-Concepts of Adolescents with Turner's Syndrome" which is being done by Linda Arlt, B.S.N., under the supervision of Doris Julian, M.N.

To participate in this study, I will attend four two-hour group education and counseling sessions, held once per week at the Child Development and Rehabilitation Center. Part of each session will be learning about Turner's Syndrome and part will be discussion of feelings involved in growing up with Turner's. Linda Arlt will be present at each meeting, and so will Penny Mock, M.S., M.Ed., who is a teacher and director of the Sex Education Project at the Crippled Children's Division. Also as part of the study, I will answer a questionnaire before and after the four week course. The questions take about 20 minutes to answer. My answers will be kept confidential. My name will not be on the answer sheet or on the records of this study.

I may refuse to participate in this study or withdraw from it without affecting my treatment at the University of Oregon Health Sciences Center or the Crippled Children's Division.

I understand that there are no risks to people involved in this study, other than their personal reactions to the information provided. I have been advised that I will be able to talk over any such reactions with Linda Arlt, Doris Julian, or Penny Mock.

I authorize Dr. Stephen LaFranchi, University of Oregon Health Sciences Center, to release medical information from my records, only as it pertains to how Turner's Syndrome affects me.

"It is not the policy of the Department of Health, Education and Welfare, or any other agency funding the research project in which you are participating, to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The University of Oregon Health Sciences Center, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the Center, its officers or employees. If you have any further questions, please call Michael Baird, M.D., at (503) 225-8014."

Linda Arlt has offered to answer any questions I may have regarding the study or the education and counseling sessions.

I agree to participate in the study.

date

signature

parent or guardian

witness

APPENDIX B
Questionnaire for the
Piers-Harris Children's Self-Concept Scale

Here are a set of statements. Some of them are true of you and so you will circle the yes. Some are not true of you and so you will circle the no. Answer every question even if some are hard to decide, but do not circle both yes and no. Remember, circle the yes if the statement is generally like you or circle the no if the statement is generally not like you. There are no right or wrong answers. Only you can tell us how you feel about yourself, so we hope you will mark the way you really feel inside.

- | | | |
|---|-----|----|
| 1. My classmates make fun of me. | Yes | No |
| 2. I am a happy person. | Yes | No |
| 3. It is hard for me to make friends. | Yes | No |
| 4. I am often sad. | Yes | No |
| 5. I am smart. | Yes | No |
| 6. I am shy. | Yes | No |
| 7. I get nervous when the teacher calls on me. | Yes | No |
| 8. My looks bother me. | Yes | No |
| 9. When I grow up, I will be an important person. | Yes | No |
| 10. I get worried when we have tests in school. | Yes | No |
| 11. I am unpopular. | Yes | No |
| 12. I am well behaved in school. | Yes | No |
| 13. It is usually my fault when something goes wrong. | Yes | No |
| 14. I cause trouble to my family. | Yes | No |
| 15. I am strong. | Yes | No |
| 16. I have good ideas. | Yes | No |
| 17. I am an important member of my family. | Yes | No |
| 18. I usually want my own way. | Yes | No |
| 19. I am good at making things with my hands. | Yes | No |
| 20. I give up easily. | Yes | No |
| 21. I am good at my school work. | Yes | No |
| 22. I do many bad things. | Yes | No |

23.	I can draw well.	Yes	No
24.	I am good in music.	Yes	No
25.	I behave badly at home.	Yes	No
26.	I am slow finishing my school work.	Yes	No
27.	I am an important member of my class.	Yes	No
28.	I am nervous.	Yes	No
29.	I have pretty eyes.	Yes	No
30.	I can give a good report in front of the class.	Yes	No
31.	In school I am a dreamer.	Yes	No
32.	I pick on my brother(s) and sister(s).	Yes	No
33.	My friends like my ideas.	Yes	No
34.	I often get into trouble.	Yes	No
35.	I am obedient at home.	Yes	No
36.	I am lucky.	Yes	No
37.	I worry a lot.	Yes	No
38.	My parents expect too much of me.	Yes	No
39.	I like being the way I am.	Yes	No
40.	I feel left out of things.	Yes	No
41.	I have nice hair.	Yes	No
42.	I often volunteer in school.	Yes	No
43.	I wish I were different.	Yes	No
44.	I sleep well at night.	Yes	No
45.	I hate school.	Yes	No
46.	I am among the last to be chosen for games.	Yes	No
47.	I am sick alot.	Yes	No
48.	I am often mean to other people.	Yes	No
49.	My classmates in school think I have good ideas.	Yes	No
50.	I am unhappy.	Yes	No

51. I have many friends.	Yes	No
52. I am cheerful.	Yes	No
53. I am dumb about most things.	Yes	No
54. I am good looking.	Yes	No
55. I have lots of pep.	Yes	No
56. I get into lots of fights.	Yes	No
57. I am popular with boys.	Yes	No
58. People pick on me.	Yes	No
59. My family is disappointed in me.	Yes	No
60. I have a pleasant face.	Yes	No
61. When I try to make something, everything seems to go wrong.	Yes	No
62. I am picked on at home.	Yes	No
63. I am a leader in games and sports.	Yes	No
64. I am clumsy.	Yes	No
65. In games and sports, I watch instead of play.	Yes	No
66. I forget what I learn.	Yes	No
67. I am easy to get along with.	Yes	No
68. I lose my temper easily.	Yes	No
69. I am popular with girls.	Yes	No
70. I am a good reader.	Yes	No
71. I would rather work alone than with a group.	Yes	No
72. I like my brother (or sister).	Yes	No
73. I have a good figure.	Yes	No
74. I am often afraid.	Yes	No
75. I am always dropping or breaking things.	Yes	No
76. I can be trusted.	Yes	No
77. I am different from other people.	Yes	No

- | | | |
|---------------------------|-----|----|
| 78. I think bad thoughts. | Yes | No |
| 79. I cry easily. | Yes | No |
| 80. I am a good person. | Yes | No |

APPENDIX C
Means and Standard Deviations
for the Piers-Harris Self-Concept Scale
Normative Group

Means and Standard Deviations
for the Piers-Harris Self-Concept Scale
Normative Group

Sample	Grade	N	Mean	SD
Small town Pennsylvania Public School Children	grade 4	275	47.79	15.19
	" 6	265	55.36	13.93
	" 8	231	52.04	13.52
	" 10	221	49.67	12.36
	" 12	<u>191</u>	<u>54.56</u>	<u>12.05</u>
	Total	1183	51.84	13.87

from Piers, E. V. Manual for the Piers-Harris Children's Self
Concept Scale. Nashville: Counselor Recordings and Tests 1969.

APPENDIX D
Data Collection Sheet

Data Collection Sheet

code # _____

DEMOGRAPHIC DATA:

Birthdate:

Year in School:

Age When Turner's Syndrome Diagnosed:

Age When Estrogen Initiated:

Number of Sibs:

Birth Order:

Two Career Choices: _____ & _____

Physical Findings from Medical Records:

PARTICIPATION:

Attendance at Group Sessions: 1 2 3 4

PIERS-HARRIS TEST SCORES:

	pretest	posttest	+/-
total score (raw score)			
percentile:			

ABSTRACT

AN ABSTRACT OF THE THESIS OF
LINDA LEE EBY ARLT
for the Master of Nursing

Date of Receiving this Degree: June 12, 1981

Title: THE EFFECTS OF GROUP EDUCATION AND COUNSELING ON THE SELF-
CONCEPT OF ADOLESCENTS WITH TURNER'S SYNDROME

Approved: _____

Doris Julian, R.N., M.N., Associate Professor, Thesis
Advisor

Turner's syndrome is a clinical condition characterized by gonadal dysgenesis, short stature, and somatic anomalies, which is the result of a chromosome abnormality.

A number of authorities share the beliefs that adolescents who are different from their peers are at risk for low self-concept, that adolescents respond to treatment in groups, and that self-concept can be improved. Adolescents with Turner's syndrome can be assumed to experience the same developmental problems as their age mates, as well as the additional stresses of being different from their peers.

The purpose of this study was first to determine to what extent the self-concept of adolescents with Turner's syndrome differs from that of their "normal" peers. Secondly, it was to ascertain to what extent group education and counseling can improve the self-concepts of adolescents with Turner's syndrome.

The experimental subjects were four girls, age 13-18, with Turner's syndrome. Their self-concept was measured by the Piers-Harris Children's Self-Concept Scale before and after a series of four group education and counseling sessions. A comparison group was comprised of

six girls in the same age group with Turner's syndrome who did not participate in the group sessions.

The self-concept scores of the experimental and comparison groups were pooled to answer the question about self-concept in Turner's syndrome in general. They were found to have self-concept scores in the average range for normal girls their age.

The girls in the experimental group did not have a significant change in self-concept after the group education and counseling sessions. Members of the experimental group cited several benefits gained from participation in the study group, which were not measured by the study.

Conclusions were drawn and recommendations for further study made.