

Girls Growing Up: A Feasibility and Acceptability Study to Explore the Antecedents of Anorexia Nervosa in Girls Aged 7 to 17

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Abstract

Objective: Prospective longitudinal research into the antecedents of anorexia nervosa (AN) is required to identify targets for prevention, early detection and treatment. Such research is hampered by the low natural incidence of AN, and the ethical complexities of research with children. A number of risk factors have been identified, but the relationship between these and the development and maintenance of AN remains unclear. To date, prospective studies have had insufficient power to differentiate risk factors from consequences of AN. The proposed "Girls Growing Up: The Antecedents of Anorexia Nervosa" study aims to identify predictors of AN and protective factors by prospectively tracking the progress of healthy genetically high risk individuals and controls. A proposed pilot study will first discover whether a series of likely physical and psychometric measures are acceptable to subjects and their families and will additionally assess whether high risk and control subjects differ at baseline on any of these measures. The present study assesses the feasibility and acceptability of the proposed research protocol by use of buzz-groups to ascertain perceptions, opinions and ideas of potential recruits.

Method: Seven buzz-groups (focus groups) were held with schoolgirls aged seven to 17, parents and teachers recruited from a co-educational school. The proposed protocol was presented as a narrated storyboard demonstrating an example research day of a fictional study participant. Group discussions were audio-recorded, transcribed and analysed in terms of study location, acceptability of measurements, recruitment and retention.

Results: The proposed protocol was broadly acceptable to all participants. Participants provided collaborative input to the study design, including: a strong preference for female researchers; discussion about the acceptability of proposed physical and psychosocial measures; a preference for a choice of study location; the suggestion of provision of a detailed timetable to reduce anxiety; and agreement that it is appropriate to advertise to parents of under-12s, but to 12 to 17 year olds in their own right. They also renamed the study and suggested means of recruitment.

Conclusion: The proposed methodology was deemed acceptable to the target group. Buzz-groups proved invaluable in exploring opinions, influencing the proposed research protocol and highlighting the value of involvement of potential participants in preparatory stages of research, particularly into the sensitive field of eating disorders.

Keywords: Anorexia nervosa; Buzz group; Focus groups; Prospective; Antecedents; Causes; Research methodology; Eating disorders

Introduction

Research into the aetiology of eating disorders (EDs) is accelerating. However, the relatively low incidence of Anorexia Nervosa (AN) makes prospective longitudinal studies challenging as these require large cohorts. In order to address this gap in the research, the Anorexia Nervosa Protocol Development Group, supported by the Scottish

Mental Health Research Network, proposed a prospective case control study to investigate the antecedents of AN in a group of healthy girls who are at genetically high risk of subsequently developing the disorder.

Preliminary work to assess feasibility and acceptability is particularly important given the age group of those at risk of onset of anorexia nervosa. Even a pilot study will require sensitive consultation with potential participants in order to justify Ethical Approval. The feasibility study we describe here did not require approval by a Research Ethics Committee as no intervention was provided to the participants. This project addresses the perceptions and opinions of potential recruits to the study, together with those of the protective adults who know them best: parents and teachers. Alongside concurrent discussions with experts in the field, this project has informed the proposed pilot study, and thus influence the eventual study-proper.

Need for prospective study

AN is a syndrome of obsessive weight losing behaviours resulting in starvation, which in turn has significant physical, psychological and social consequences [1,2]. As the commonest cause of inpatient admission to child and adolescent psychiatric services, it brings sizable cost to the health service [3]. Mean age of onset is about 15 years, with up to 90% of cases diagnosed in girls [4]. Recovery typically takes around six years [5], but chronicity is common and mortality is the highest of any psychiatric disorder: 10-20% die prematurely [6]. For those who do recover, physical, psychological and social sequelae are often long-term [7].

Recent years have seen major advances in the understanding of AN, in particular its neuropsychiatric basis [8]. However, there remains limited evidence for effective prevention or treatment of AN [9]. Early management has been shown to reduce chronicity [7], but given the significance of life-long complications, prevention is clearly the preferable option.

A number of risk factors have been identified, spanning genetic [10,11], personality [12], family [13,14], psychosocial [7,15], and cultural [16] factors. However, little is known about how these factors relate to the development of, avoidance of, or recovery from AN. A meta-analysis of risk and maintenance factors in eating pathology identified a lack of specific prospective studies into risk factors for AN [16]. Jacobi, Hayward, de Zwaan, Kraemer and Agras [17] recognised that outcomes in risk-identification studies rarely differentiated between AN and other eating disorders (Eds), and that those that did had insufficient power to justify risk factor analysis.

More recently, prospective studies, such as that by Nicholls and Viner [18], have been limited both in terms of their ability to differentiate risk factors from the consequences of AN, and in the low incidence of the cohort developing AN. Such limitations highlight the importance of conducting sufficiently powered prospective studies into the risk factors of AN. Already the British Paediatric Surveillance Group has provided a baseline from which to monitor changing trends in incidence of EDs [19]. Stice, Marti, Shaw and Jaconi [20] carried out a prospective study following a group of US schoolgirls for eight years, which indicates that 11% develop an ED of some sort during their teens, whilst only about 1% develop AN..

These useful studies do not provide answers about the causation of AN. This necessitates an AN-specific, prospective study with sufficient power to allow analysis of risk factor data.

Plan for prospective high risk study

Known risk factors can be classified according to their chronology within an individual's developmental trajectory as: predisposing, precipitating, and perpetuating factors [16]. However, whilst we might predict that those "high risk" individuals exposed to precipitating factors will go on to develop AN, in reality this is not always the case [2]. In individuals who avoid developing AN, risk factors must be offset by protective or resilience factors [16]. This hypothesis, shown in Figure 1, provides a framework on which to build a greater understanding of individuals' developmental journeys towards health, or towards AN. Expanding our understanding of the factors within this model, may identify potential targets for preventative interventions, early identification and treatment.

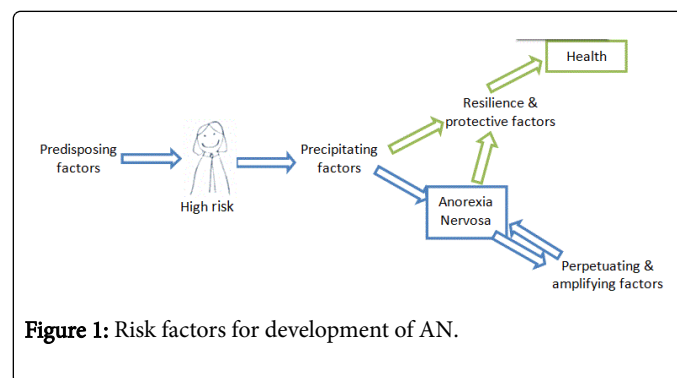


Figure 1: Risk factors for development of AN.

The proposed future study works on the premise that "high risk" subjects can be identified by using current understanding of genetic risk factors; twin studies have shown a higher concordance for monozygotic than dizygotic twins, and individuals with a first degree relative who has had AN have ten times the risk of the general public [1,2]. Since 90% of those with AN are female, and onset is usually during adolescence [17], the study will exclusively target females between the ages of seven and 17. The study will aim to compare healthy genetically high risk females to controls, identify predictors of AN, and determine protective factors. Data will be gathered from high risk individuals and their families, and matched controls and their families, at initial and annual follow-up assessments.

Need for informative feasibility and pilot studies

To facilitate and maximise the output of such sensitive and complex research, preliminary work is needed to gauge the feasibility and acceptability of the proposed methods of recruitment, measurement, and retention of participants. This is particularly pertinent considering: the uniqueness of the study; that subjects will be under eighteen, and the majority under 16 years of age; that girls will span both pre and post-pubertal developmental stages; that assessments are of a socially sensitive nature and that psychometric as well as physical assessment tools may be validated for particular age groups. Even clinically experienced researchers may be over-, or under-sensitive to various concerns of potential recruits and their families. Identifying the hopes and fears of participants, will allow appropriate adaptation of protocols and benefit from the creative collaborative input of the young people and those who care for them. We have thus proposed a 3-stage process:

A feasibility study to invite consultation with potential subjects, including parents, clinicians and teachers. This would inform design of A Pilot study to pilot identified and approved measures in up to 20 families, in order to ensure that measures, recruitment processes,

timing and other aspects of the interventions were indeed both acceptable and informative. Power calculations would be made, and assessment of any baseline differences between High risk and control subjects would be investigated. These studies would then inform the substantial multi-centre prospective study which would test out a range of potential risk factors for the development of and recovery from anorexia nervosa over a 5 year (and potentially longer) period.

Aim

The aim of this feasibility and acceptability study is to identify perceptions, opinions, and ideas of potential recruits when presented with the proposed protocol of the “Girls Growing Up: The Antecedents of Anorexia Nervosa Study”.

Methods

Potential risk factors were identified from the literature review, and age-appropriate psychometric measures for these were identified and broadly described for the benefits of participants. A range of desirable physical examinations such as weight, height, buccal smear sampling, blood tests and so on, was also described in terms that girls would understand. These investigations were incorporated into the ‘storyboard’ presentation.

Recruitment

A local co-educational fee-paying school was invited to participate because its Junior and Senior divisions cover our target age range and the likely similar demographic of potential recruits to the study-proper. The school also offered access to the input of parents and teachers as well as girls.

Preliminary discussions with senior staff were taken into account when designing both information sheets and buzz-group content. Individual participant information sheets about the buzz groups were issued for junior girls, senior girls, parents and teachers, and distributed electronically by the school. Volunteers were invited to attend the appropriate buzz-group. (Table 1)

Group 1	Girls aged 7 – 11 inclusive	Held in parallel with Group 5, so that parents were present at the other end of the hall, for reassurance and convenience, but allowing privacy
Group 2	Girls age 11-13 inclusive	Groups 2, 3, and 4 were held in parallel, with joint presentations as a plenary, followed by age-specific break out groups. These groups were held in the school lunch hour, over refreshments
Group 3	Girls age 13- 15 inclusive	
Group 4	Girls age 15-17 inclusive	
Groups 5 & 6	Parents of girls aged 7 - 11	Group 5 (afternoon session) was held in parallel with Group 1, but some parents preferred discussion in an adults only setting (Week night evening)
Group 7	Parents and teachers of girls aged 11-17	Held in school staff room, one week night evening
Preliminary meetings and further discussions with primary school teaching staff were held separately, not following the ‘buzz group’ protocols.		

Table 1: Constitution of Buzz Groups

Ethical considerations

The study took place under the auspices of the Medical School of the University of Edinburgh. We were advised by the Chair of the local ethics committee that their approval was not required for the feasibility study which would then inform the ethics application for the pilot study. This was because the study involved consultation with participants about interventions and measures, rather than carrying out any interventions on the participants.

Little has been published regarding the ethics of buzz-groups [21]. Care was taken to ensure that all participants had volunteered, and had not been coerced into taking part. In particular, junior school parents were met before their daughters in order to ensure that both the child and her parents were happy for her to take part. Similarly, it was borne in mind that disclosures were shared with all participants, not just the researcher, and that there is the potential for distress in response to what other participants would contribute [22].

The ‘Buzz-groups’

7 buzz-groups (also termed “focus groups”) were formed in keeping with the principles described by Vaughn, Schumm and Sinagub [23] as an informal assembly of a small, relatively homogeneous, group of usually six to 12 participants whose perceptions, feelings, attitudes and ideas are elicited by a moderator with prepared questions and prompts.

Procedure

After a welcome by the lead researcher, the protocol was introduced by a senior medical student well-briefed in the methodology of the study-proper. An example research day of a fictional study participant was presented in the form of a narrated photographic story-board which was suspended at intervals to allow discussions in groups of between three and 12 participants. The two moderators acted only to encourage discussion, put forward new questions, and keep discussions on topic. Buzz-groups lasted less than the maximum recommended duration (45 minutes for under 10s [23]; 90 minutes for over 10s [24]). Each buzz-group was audio-recorded then subsequently transcribed and the recording deleted. Anonymous written feedback was also solicited from each group.

Analysis of results

Discussions were transcribed without deviation. Comments were then assigned to themes - broad categories dependent on their content, including study location, acceptability of measurements, advertising/recruitment, and retention. This data was then triangulated by comparison of comments from (i) different groups, and (ii) anonymous written feedback solicited from each group. Credibility was checked by means of presenting comments or themes from earlier groups to later ones, allowing comments to be compared. Overall, there was a high degree of agreement between groups.

Results

Sample and process

Initial consultations with school staff prompted some immediate changes both to the process of the Feasibility Study and to the design of the Pilot and Main Studies proposed in the future. Most notably, the study title was changed from “Antecedents of AN”, to “Girls Growing Up”. This was recommended as a more attractive title, both

emphasising the positive interest of the study in resilience as well as vulnerability, and in addition broadening the interest from a narrow focus on illness trajectory to a general curiosity about adolescent development.

'Buzz-groups'

Figure 2 provides an overview of the characteristics of the participants. A total of 30 girls aged between seven and 17 years, and 25 adults took part. Seven buzz-groups were then held (Table 1). In most groups there were some participants who knew each other and some who did not. Discussions were lively and productive, with an overwhelming enthusiasm for the project. Potential participants were more positive and expressed fewer reservations than clinicians.

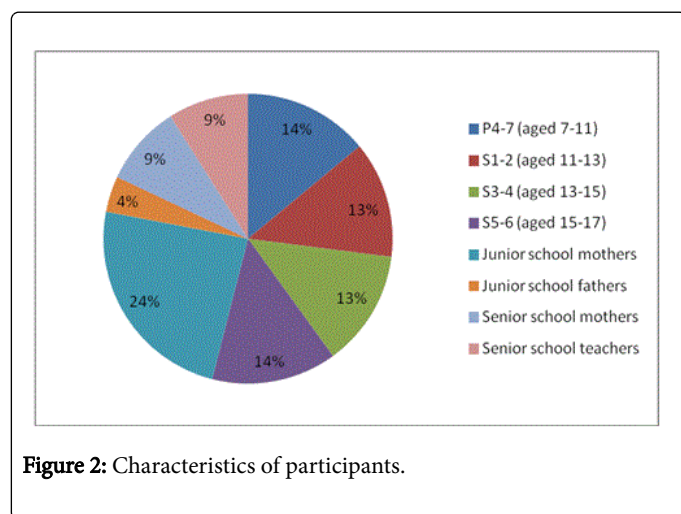


Figure 2: Characteristics of participants.

Programme Content 1 – format and process: Study location, genogram

Overall, most comments and suggestions fell into predictable categories and were similar in recommendation, mainly differing in terms of their wording and prioritisation.

Study location

Most girls were happy to travel to a Scottish study-centre in Glasgow. Some wanted siblings present, others preferred not, but recognised potential difficulties arranging childcare. Senior girls suggested a number of local centres might be more convenient. Older teenagers had concerns with disruption to homework, sport and socialising, but could accept annual visits. This group considered home visits intrusive, but all groups thought that the study-centre itself should be made "homely". Both older girls and teachers commented that their confidence and answers may reflect the environment. Most junior parents preferred to be visited at home, or attend a local centre. Senior parents and teachers felt a local centre was less time consuming, but were also attracted to an all-expenses paid trip to Glasgow. One parent, whose eldest daughter had been visited at home as part of a mental health assessment thought it valuable to do both study-centre and home visits.

Genogram

The genogram-drawing exercise promoted lively discussion from all groups. All but the youngest children had drawn their family tree before; most had done so multiple times. One of the youngest girls was

adopted, and discussed how, for her, two 'genograms' could be drawn. Younger teenagers suggested that although certain things may be sad or embarrassing for their parents, they themselves were unlikely to be concerned. Older groups said their parents might become upset talking about mental illness such as dementia, and recent bereavement. They were concerned that separated parents might be distressed. Adult groups raised concerns that 'family secrets' might pose problems. All except the youngest girls said it would be helpful to be warned in advance that family history would be discussed. A community paediatrician present in the senior parents group expressed concern about the reliability of self-reported information.

Programme Content 2 – physical and psychological measures

Physical Measures

Few participants expressed any concern over the physical measurements. Even the youngest girls had a rudimentary understanding of DNA, and nobody from any group raised concerns with anonymised genetic testing.

The Primary age group had been weighed and measured at home and at their GP surgery, and none had any concerns. The 11-13 year old group were also confident about the measurements, although reported that 'some of their peers might not like it'. Both the older teenage groups emphasised the importance of sensitive weighing - girls of their age would be concerned about their weight, and may be self-conscious, nervous, and worried about being overweight.

All groups thought they would probably like their mothers to be present at the first session, but as they became more confident they would be happy to be measured alone. One group suggested that a happy median would be that a parent could sit outside the weighing room with the door open, and read a magazine. Older girls told us they would prefer the opportunity to talk openly with the researcher without their parents present. This group were also very keen that 'normal conversation' was maintained with the researcher throughout the measurements, and that neither they nor their parents were told the results. Senior parents and teachers were satisfied with our proposed methods, provided results were kept securely

Psychological testing

This was generally well-received. Girls had no qualms about talking about intimate matters with a professional stranger in a confidential setting. All senior school girls groups considered continuity of researcher to be important. Girls in their mid-teens thought talking about food and exercise might be sensitive, whereas 16 and 17 year olds were more sensitive about talking about boyfriends and problems at home. Several girls in this group said that they would probably lie when discussing such topics, and considered it imperative that researchers were well-versed in knowing when they were "lying or dodging" a question. Parents in general were eager that appropriate support would be available if participation in the research highlighted any problems. Senior school parents and teachers suggested that requesting access to school reports might save time spent on intellectual testing and add valuable insight into a girl's school life.

Programme Content 3 – Publicity, recruitment, retention and incentives

Advertising and Recruitment

The junior girls made no comments about advertising or recruitment. The senior girls all agreed that the title “Girls Growing Up” was appropriate, accurate, and spanned the age range. Young senior girls thought it is important that the study did not sound to their friends as if they were attending hospital for a medical reason, and that it did not feel like you were going to “be analysed”, or that there were right or wrong answers. The oldest girls’ free associations to the study title were: “height... attitudes to different things... confidence... when you got your periods... breast sizes... things people are into”. They thought the title was both medically related and accurate, whilst not being frightening.

Parents were more specific about how the study might appeal to potential participants’ altruism as well as to their interests as a family.

Junior school parents were mostly movingly concerned simply to volunteer their own families to take part. They were concerned that we should not exclude families because of parental separation, adoption, or children with diagnosed genetic conditions. Similarly, these parents were also eager to “spread the word” to friends, even offering to contact parents of a recently closed local girls’ school.

Both groups of parents and teachers thought it appropriate to target advertising to parents of under 11s, and over 11s themselves. They suggested a range of potential means of recruitment including: doctor’s surgeries, Facebook, Twitter, gymnastics clubs, “Families” magazine, dance groups, news clips, schools, sports teams, orchestras, swimming, and networking between parents.

Retention of study participants

Senior school parents and teachers suggested that incentives might include a choice of vouchers or money, as well as recognition as ‘public service’ in organisations such as Girl Guides and Duke of Edinburgh Award. It was also suggested that participants have the chance to meet each other, thus encouraging each other to stay involved. One teacher also commented that consenting to lifelong access of a participant’s GP notes might allow a certain level of follow up even after ‘drop-out’ from the study.

Discussion

This study demonstrates the use of buzz-groups as a method of conducting a feasibility study for research with children and adolescents. In particular, this method has informed the acceptability and feasibility of a proposed protocol for the forthcoming Girls Growing Up: The Antecedents of Anorexia Nervosa Study. Children in the youngest group were able to say whether or not suggestions were acceptable, and could offer mainly associative comments. Discussions in the senior school groups ranged from the confident yet still mainly associative comments of 11 and 12 year olds, the more reserved exchanges of young teenagers, to the independent, assured and reflective debates of the eldest participants. Parent and teacher groups were similarly informative, with an added dimension of mature and professional experience. Happily, all these groups were particularly supportive of the planned research.

The following key messages were incorporated into the design of the pilot and main study protocols:

Subjects appreciate different options of study venue including:

- an expenses paid weekend in Glasgow

- a home visit (at least one in course of study);
- a one-day visit to a local study-centre.

All our proposed physical measurements and psychosocial assessments were deemed acceptable. An accurate, detailed itinerary with or without a video interview of a previous participant (potentially from the pilot study) for children, and clear information regarding support and confidentiality for parents, would reduce pre-visit anxiety. Happily, although it was envisaged that participants may be preoccupied by their results, this was not the case.

Consent should be sought separately on each annual visit. Withdrawal of consent for measurements may provide useful insight (for example, if a girl is insistent that her weight is not measured). It was deemed appropriate and acceptable to approach parents of under 11s, and over 12s themselves, outlining incentives (e.g. vouchers) at the outset. “Girls Growing Up” was considered a positive and universal title, but a second tag-line vaguely implicating medical or healthcare should be considered. It is important to remain aware that some families seek to participate in the hope of therapeutic benefit; the study must remain transparent that it is for research purposes only throughout advertising, recruitment, and assessment.

Limitations

The role of buzz groups is increasingly well recognised in the field of qualitative research, and is particularly useful for eliciting opinion and experience [25]. However, drawbacks of this method are inevitable. Firstly, inferences cannot be drawn about the larger population based on an individual group [26], thus, whilst the opinions of the participants are valued, they may not represent those of actual recruits to the study-proper.

Furthermore, whilst group interaction is generally deemed to be an advantage [22], factors such as intimidation [27] may undermine results. Participants may also take on points raised by others in the group, rather than expressing their own opinion, leading to a false sense of priority and importance [27]. However, researchers transcribing the discussions noticed that whilst most participants represented themselves as confident and open, they tended to express any reservations by attributing these to ‘other girls’ or ‘some people’. This may represent projection, but may also be a realistic recognition that individuals volunteering for our buzz sessions probably represented the more confident pupils, and were trying to fairly represent their less extrovert peers. In order to allow for this possibility, we have arranged to interview on family in more depth, following a trial run of the proposed measures at the Research site itself. Moreover, we have built into the Pilot Study protocol some explicit arrangements for eliciting in-depth feedback from participants about their experience of the process. This will allow further refinements before the larger study is launched. We did not request demographic information. It is likely that there was a higher representation of participants from affluent backgrounds, although some girls were likely to be in receipt of scholarships or bursaries. We did not seek to gain opinion specifically from ‘high risk’ individuals (although at least one known high risk girl and her mother did voluntarily participate).

The reliability of qualitative data is notoriously difficult to analyse. Two methods identified in focus group literature include “triangulation” and “credibility” [22]. Triangulation using transcribed narratives is described in our methods section. Credibility here was checked by means of presenting comments or themes from earlier

groups to later ones, allowing comments to be compared [22]. The frequency of consensus suggests adequate reliability.

Conclusions

The results of this feasibility study were submitted to the West of Scotland Research Ethics Committee to inform our proposal for the Pilot Study. It was gratifying to receive Ethical Approval and to be congratulated on the appropriateness and thoroughness of the Feasibility Study. Buzz-groups proved to be useful in exploring girls', parents', and teachers' opinions regarding the proposed research protocol, highlighting the importance of including target groups/potential research participants in the preparatory stages of research. This project has successfully influenced methodology of the proposed study. It also demonstrated that the proposed protocol, methodology, measures and study location would be acceptable to the target group and therefore suggested it would be feasible to conduct a prospective study in the important but sensitive field of AN.

Some public health implications emerge from this work. The search for preventative and early intervention strategies for anorexia nervosa could in the future help to stem the growing epidemic of this disorder. There are also findings of a more general application. We have observed that secondary school communities – including teachers and parents as well as pupils – regard it as a worthwhile educational experience to participate in the field of mental health research, and can provide surprising and thoughtful advice into study design. We strongly recommend that similar work be carried out in preparation for all research involving young people. Their energy, creativity and generosity are invaluable, as is the insight which they provide into the social culture which is uniquely theirs as they, and their adult supporters, navigate different developmental stages.

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