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TITLE

Experiences of adolescents living with Silver-Russell syndrome

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KEYWORDS

Qualitative research; growth; psychology; adolescent health; genetics.

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ABSTRACT

Objective: The psychosocial impact of growing up with Silver-Russell syndrome (SRS), characterised by growth failure and short stature in adulthood, has been explored in adults; however, there are no accounts of contemporary lived experience in adolescents. Such data could inform current healthcare guidance and transition to adult services. We aimed to explore the lived experience of adolescents with SRS.

Design/setting/patients: In-depth, semi-structured interviews were conducted between January 2015 and October 2016 with a sample of eight adolescents aged 13 to 18 (five girls) with genetically confirmed SRS from the UK. Qualitative interviews were transcribed and coded to identify similarities and differences using thematic analysis: codes were then grouped to form overarching themes.

Results: We identified four themes from the interview data: (1) the psychosocial challenges of feeling and looking different; (2) pain, disability and fatigue; (3) anticipated stigma; and (4) building resilience and acceptance. Despite adolescents accepting SRS in their lives, they described on-going psychosocial challenges and anticipated greater problems to come, such as, stigma from prospective employers.

Conclusions: Adolescents with SRS may experience psychosocial difficulties from as young as 10 years old related to feeling and looking different; pain, disability and fatigue; anticipated stigma and future challenges around employment. We discuss these findings in relation to recommendations for the care of adolescents with SRS to prepare them for adult life.

INTRODUCTION

Silver-Russell syndrome (SRS) is a rare genetic condition characterised by slow growth in utero leading to poor post-natal growth, short stature in adulthood, triangular facial appearance, asymmetry, feeding difficulties(1), low muscle mass and poor muscle function(2). A recent study estimated SRS incidence as 1:15,866(3) – higher than previous estimates(4) – with males and females equally affected(1). Two molecular abnormalities cause the majority (60%) of SRS cases(5), but a significant minority of patients have no known molecular cause(1). Management of SRS during childhood focuses on optimising final height through nutrition and growth hormone (GH) therapy.

Our recent qualitative research showed that adults living with SRS dealt with psychosocial challenges through childhood and adolescence; they had appearance-related concerns beyond their height and experienced difficulties in forming romantic relationships in adolescence and into adulthood(6). Women reported experiencing pain and disability, impacting on employment and familial relationships. As part of our broader programme of research(6, 14), we interviewed adolescents (aged 13 to 18 years) to explore their lived experience of SRS, aiming to understand their particular concerns to help adolescents and their families when making difficult treatment decisions.

There is a level of uncertainty regarding issues and challenges requiring the focus and attention of health professionals working with people living with SRS, due to a dearth of published literature reporting on the lived experience of children and adolescents living with short stature conditions, such as SRS. One qualitative study of 29 young women with Turner's syndrome showed that participants were troubled by teasing in school about being small,

which for some persisted into adulthood, and about infertility resulting in fear of initiating romantic relationships and remaining single(7). Survey studies found that adolescents living with Turner's syndrome report problems with social functioning;(8) reduced health-related quality of life (QoL)(9); and no impact of prior GH on QoL in adulthood(10).

We set out to explore and evaluate the lived experiences of adolescents living with SRS to inform clinical management up to adolescence and beyond. Qualitative methods for data collection and analysis allowed for rich data to be generated and examined to gain an in-depth understanding of the lived experience(11-13) of SRS.

METHOD

Public and patient involvement (PPI)

A member of the Child Growth Foundation - a UK charity that supports people affected by child growth conditions - who had personal experience of a growth condition, was also part of the research team. This charity member was involved in the development of the funding application, attended project steering group meetings, development of patient information leaflets and consent forms, advised on recruitment and analysis and was involved in the dissemination of project findings.

Identification of adolescents with SRS

Participants were recruited from a larger study investigating the health consequences of SRS in young people(14) and from a patient support group. Research and development approval was secured from University Hospital Southampton NHS Foundation Trust (study sponsor) and, for the 23 UK Genetics Centres, via the NIHR UK Rare Genetic Disease Research Consortium Agreement ('Musketeers' memorandum'). Individuals were identified across the

UK through: (1) study information disseminated by a patient support group: the Child Growth Foundation, UK; (2) prior recruitment to an existing national study 'Imprinting Disorders: finding out why' with expressed interest in further research; (3) review of positive molecular genetics tests at the Wessex Regional Genetics Laboratory; and (4) contact with regional genetic centres and paediatric endocrine centres at existing genetics research sites.

Using the first two approaches, participants were sent study information by post and invited to contact the study team or were contacted by telephone if they had previously given permission. For the other two approaches, the patient's overseeing clinician was contacted and asked to post study information to their patient.

Study Interviews

Interviews were chosen as they allowed the researcher to: focus on drawing out individual experiences; explore specific concerns or issues; flexibility when wording questions; and add questions about relevant topics that arose(13). As SRS is a rare condition and individuals may be known through support groups, robust confidentiality measures were instituted, including numerical participant identification and the use of age ranges. The interview schedule addressed the impact of SRS on key aspects of a participant's life (education, work, friends, family, intimate relationships). The interview schedule was piloted with people living with a chronic health condition, before commencing recruitment to our adult lived experience study (15). Piloting the schedule allowed us to assess how appropriate the questions were, if they were in an order that made sense and, to have some practice in asking the questions. We made several adjustments based on interviewee feedback, for example, taking out questions that were difficult to answer, were repeated and reordering questions. Each interview took

30-60 minutes and was audio recorded. Interviews were conducted by a trained female health psychologist (LMB) experienced in discussing sensitive health issues with patients. We gauged parents' thoughts about the interview; although this may have placed parents in a 'gatekeeper' position, none declined an interview on their child's behalf. Parents and adolescents had the option of having a parent/trusted person present for the interview, and two participants were interviewed with parents present (see Figure 1 for more considerations). All participants were provided with an information sheet and the opportunity to discuss the research and ask questions. Written consent/assent was gained from adolescents and their parents. Participants were reassured that they could discontinue the interview at any time and that it would be audio recorded, but this could be stopped at their request.

[Figure 1 here]

Analysis of study interviews

Interviews were transcribed and analysed thematically using the Braun and Clarke method(11). Codes were generated from the first few interviews and then refined as subsequent interviews were analysed. Codes were then grouped to create categories and developed into four overarching themes. To ensure rigour in developing themes, coding and categories were independently reviewed by three researchers (LMB, AF and EJ). Tracy's (2010) criteria were used to enhance the validity and overall quality of the study(16). Qualitative data were managed with NVIVO software (QSR International, V.11.3.2 (1888) for Mac). To triangulate our findings, we presented them to adults and adolescents living with

SRS, as well as their families. Feedback from this reassured us that our conceptual work reflected participant's lived experiences.

RESULTS

Study participants

Eight participants (five girls) aged 13 to 18 years were interviewed (see figure 2 and table 1 for details). Six participants were recruited from a broader study (of nine adolescents, six agreed to participate and three were uncontactable) and two from a patient support group (number of participants declined is not known as adolescents were asked to approach the researcher if they were interested in taking part). Three participants had a loss of methylation at 11p15, four had maternal uniparental disomy of chromosome 7 and one was genetically confirmed with the specific diagnosis not revealed to the researcher; six had received GH treatment, one had not and for one was unknown.

[Figure 2 here]

Table 1. Participant information

Participant (F=girl, M=boy)	Age Range	Height Range (CMs)	Genetic Diagnosis	Educational Type	Growth Hormone treatment
P01_F	16-18	152.4-154.4	MatUPD7[1]	Special	Yes
P02_F	13-15	152.4-154.4	H19	Regular	Yes
P03_F	13-15	152.4-154.4	H19	Regular	Yes
P04_M	13-15	159.4-164.6	H19	Regular	Yes
P05_M	16-18	159.4-164.6	MatUPD7[1]	Regular	Yes
P06_F	13-15	152.4-154.4	MatUPD7[1]	Regular	No
P07_F	16-18	152.4-154.4	Unknown[2]	Regular	Unknown
P08_M	16-18	159.4-164.6	MatUPD7[1]	Special	Yes

[1] Individuals with MatUPD7 have mild learning disabilities more commonly than those with 11p15 LOM (17)

[2] Genetically confirmed but unknown if H19 or MatUPD7.

Ethical approval was granted by the NHS Research Ethics Committee South Central – Hampshire B (REC reference: 13/SC/0630).

Findings

Four themes were identified: "*I'm different! Why?*"; *"Oh, are you disabled or something?"*; "*I hope it doesn't affect getting a job*"; and *"You're not always going to be perfect*".

1. The psychosocial challenges of feeling and looking different: "*I'm different! Why*?"

Participants described feeling different from those around them (Box 1), which was exacerbated by how others treated them. For example, participants reported they had previously experienced bullying: "*I got called names […] small, midget, all that sort of stuff*" (P05_M), however most said they were not being bullied currently. Participants described feeling and being treated differently from around age 10-12, which caused some to change their behaviour: one reported feeling that she must go above and beyond what was expected of her academically, to combat the perception that she may have special needs: "*She [teacher] just treated me like I was a total idiot*" (P02_F). Another facet of this theme was looking different from peers. Participants discussed wanting to change their "*spaced apart*" eyes or "*big forehead*". Two of the girls in the sample felt that they would fit in if they were taller; describing how being smaller than their peers led to them being treated as someone younger.

Box 1. Quotes linked to the text regarding the psychosocial challenges of living

with SRS	
Having a stammer[1]	*It's affecting me sometimes talking in class, because I don't really want to, in case people […] laugh at me because I don't really want to be trying to start saying one word and so I tend to not really speak that much. And I don't like it when teachers pick on you, because that just makes me go 'I just can't do it'.* (P03_F)
Being unhappy with appearance started aged 10	*Because children are always looking for differences, it doesn't bother me [having SRS]. When I was ten, I'd get really bothered about it. I would think 'Oh why is it me, why did I have to have it?' and it was like 'I'm different, why!' [N]ow it's kind of gone down again.* (P02_F)
Feeling left behind	*P01_F's mum: Your friendship went off a little bit, as her, I think P01_F's gap was widening, because they were all going off going out to the cinema and parties.* *P01_F: And they didn't invite me much.* *Interviewer: How did that feel?* *P01_F: Sometimes I felt sad about it.*
Feel different to others with SRS	*I think I felt like they felt they were like different to me - like they got different - I don't know how it works, but I did feel like some people were like different than other people. Like you know I've met some people who were just like smaller than other people, but then I met other people that had other stuff and all of that.* (P05_M)
Treated differently	*It was different in different years, so in Year 7, people used to give me very odd looks and kind of dirty looks, for no other reason than I was just small. People used to treat me a lot differently. The most noticeable time that this happened was I was in a football team for about three years, one girl there refused to acknowledge that I was older than I looked. It's surprising really. You get very different reactions when you're a certain height.* (P07_F)
Appearance	*It was more when I was younger - it was more noticeable. So, my eyes were a bit further apart when I was younger. They've gone more; well they've gone more normal now. But they were more spaced apart when I was younger.* (P07_F)

[1] There may not be a specific link between SRS and stammer, but 40% of children with SRS have delayed speech (17).

2. Pain, disability and fatigue: "*Oh, are you disabled or something*?"

The perception of feeling different may have been cemented by the experience of pain and disability and others' reactions to this (box 2). Almost all the girls in the study reported experiencing pain, whilst none of the boys did. Pain often encroached on day-to-day activities, such as walking to school, handwriting, and physical activity: *"[pain] stops me walking and playing [sports]*" (P07_F) – sometimes prompting comments from others. Participants described adaptations to pain, including using a laptop because of painful wrists; using a wheelchair to avoid the discomfort of being out for a whole day; and avoiding activities that exacerbated the pain. P01_F reported having difficulties with playing games after school: "*I broke my ankle and […] it kept on happening in a year it kept on happening […] so they said I needed ankle supports […] and I needed knee supports because I've been bending my knees backwards*". For some, the inability to participate fully in physical education was no great loss: "*[T]hey're all able to like throw things, all the things and I can't. But that doesn't really bother me because I'm not really into sports in the first place*" (P03_F), but it is possible that not being able to take part in sports from an early age, we speculate, may have led to a dislike for this subject. Others, who would have liked to be more involved in sport, were fearful of exclusion due to perceived lack of ability.

Box 2. Quotes linked to the text regarding pain, disability and fatigue	
Pain during daily activities	*I struggle to walk sometimes, like really struggle. I'll be fine for about thirty seconds, and then I get a burning sensation going up my legs, and they go, my legs go inwards, so I can't, and then I can't walk.* (P07_F)
Adaption due to pain	*Well my wrists, I can write short passages but writing longer, I find it really difficult, so I'd use a laptop for it, because it just hurts.* (P03_F)
Comments from others	*I mean my feet hurt from just walking home today […] and like [to] be able to walk long distances, because my feet really hurt after a short amount of time. And PE [physical education] is noticeable, like someone asked me, they came up to me and said 'Oh, are you disabled or something?' in PE.* (P02_F)

Physical disability	*It really bothered my dad actually because he was going 'She's not disabled, why is she in a wheelchair?' And I don't think it actually bothered me, but the fact that people stared did, because it was a real difference, because if you are just walking around no-one stares at you, but I was pushed into the disabled queue, and all the kids were looking at me getting out of the chair, and I just went 'Oh, I feel a bit on the spot.'* (P02_F)
Tiredness	*I used to do karate and gymnastics and I used to play football, but I've stopped them now […] because I normally get tired easily. I have to stop all activities.* (P08_M)

3. Anticipated stigma: "*I hope it doesn't affect getting a job*"

Some participants anticipated future stigmatisation or discrimination because of having SRS (Box 3). Some had concerns that symptoms such as pain might make working a challenge; others did not anticipate SRS being a barrier to employment and relationships. Participants did not anticipate SRS having an impact on them dating in the future unless "*guys don't like small girls or something. I don't think so.*" (P02_F). Three participants had started to date, although periods of dating were brief (four weeks) and three confirmed they had not yet started dating. P06_F and P08_M declined to elaborate, with P06_F saying, "*I'm not really fussed; like I don't really bother*" and P08_M said he would "*rather be single*". P04_M thought that he had no spare time for dating but knew that some of his friends had started.

Box 3. Quotes linked to the text regarding future challenges	
Worries about pain affecting employment prospects	*I hope that doesn't affect getting a job because of my wrists - my wrists do hurt, writing and that, and I just wonder. Probably either in vetting, maybe. I hope to have a good future. Hope it doesn't really affect me.* (P03_F)
Anticipated stigma	*I also hope that because you see stuff like people giving jobs to taller people because they think they're more able and stuff. I just hope people won't judge me because of that. I would tell them that, I think that's the main thing, if I tell them that I had this thing [SRS], that they'd say 'Oh, she's weird, she has a genetic condition'.* (P02_F)

Worries about height affecting employment prospects	*I think one of the main things is, it might sound crazy, but I don't want to not get a job because of the size that I am, because I want to be a* [profession] *when I'm older, and I don't know if it will or not, but I just don't want it to affect me in the long-run, but I don't think it will.* (P05_M)
Independence for those with MatUPD7	*I hope to start making my own doctor's appointments. because I will be living in a house before very long [and] working in a phone shop.* (P08_M)
Dating	*No, I don't actually really have any relationships of that kind. I've only got friends. I think some of [my friends] have had boyfriends and girlfriends, but I don't really hear much about them.* (P04_M)

4. Building resilience and acceptance: *"You're not always going to be perfect*"

Of the strategies for responding to adversity identified in the data (Box 4), many could be classed as coping or adaptive strategies, such as capitalising on social support. Participants appreciated opportunities to be with people like them e.g. at school with a person who is also hard of hearing, or at a convention with others who also have SRS. While some participants described downward social comparison to others – e.g. P02_F feeling "*quite well off*" compared with other girls with SRS – others described a form of 'upward comparison'; comparing themselves with people they believed to be more fortunate than themselves. One participant described comparing themself unfavourably with their unaffected sibling: "*I used to think it's not fair, because* [they've] *got nothing wrong with* [them] *and I've got everything."* Nonetheless, these participants seemed to have found some acceptance by understanding that no one is 'perfect': "*I've learnt that you're not always going to be perfect, there's always going to be something.*" P01_F described anxiety and confidence issues whilst in mainstream secondary school, but, after starting special education, where she felt she was "*one of the more able students*", she stated her confidence improved. Most participants described the significant role of their family in supporting them through treatment, medical appointments, and other challenges, and also reported valuing the support of friends.

Box 4. Quotes linked to the text regarding resilience	
Downward comparison	*I haven't got Russell Silver Syndrome as bad as some of the other people in there* [Child Growth Foundation Convention]. (P06_F)
Social support – Child Growth Foundation Annual Convention	*Because you can talk about it more. Because sometimes when you're talking to your friends about it, they're always like 'Oh no', and they're not really interested because probably it's just my friend who has something. But the people there, they have it too, and you can share experiences with them.* (P02_F)
Social Support – friends like me	*But one of my friends, who I've known before Secondary is in my Year, and she's also hard of hearing, so that's nice for me, because it's someone who I can relate with*. (P03_F)
Social Support – friends	*I think I've got quite a few friends as well.* (P04_M)
Social support - family	*My mum and dad have been there for me all the time, through my injections and all through the growth and all that. I think it might have impacted on them, the injections, because I don't think they liked me taking injections. But I feel like it's impacted them in a good way, because they've seen all the changes that have happened to me, and they're quite proud of me.* (P05_M)

DISCUSSION

To our knowledge this is the first study exploring contemporary experiences of adolescents living with SRS. Whilst resilience was described, most participants described psychosocial challenges and anticipated more to come. For example, stigma owing to their height, having a genetic condition, and feeling different from their peers. Most of the girls in the sample reported experiencing pain and discussed how disability played a part in their lives. Participants described both adaptive and maladaptive ways of coping with challenges, such as downward and upward social comparison and accessing social support.

Participants described feeling different from peers, and being treated differently, often as early as age ten years. Some reported experiencing bullying associated with SRS when younger: e.g. appearance, hearing problems, having a stammer. These findings parallel those

of our adult study (6) and reinforce the conclusion that childhood and adolescent challenges are likely to have a significant psychosocial impact on adults living with SRS(6). Previous research on patients with Turner's syndrome suggested that QoL outcomes could be improved by addressing concerns about height by age 6-12 years at the latest(18, 19). Our studies suggest likewise; psychosocial evaluation and support by age 10 years would assist during adolescence and in the transition to secondary school.

Participants reported coping with feeling different by comparing themselves to others less fortunate than themselves, capitalising on social support from friends and family and accessing support groups. These skills, which foster resilience, are important to positive adjustment when feeling or looking different (20). Accessing support groups can be particularly beneficial – some of the participants in our study attended the Child Growth Foundation Annual Convention and were members of online support groups: participants may have gained social capital by forming new friendships (21), downward comparison can be made with those in a similar situation, increasing self-esteem (22), upward comparison can increase feelings of hope and motivation (23) and simply being with others who are similar may give people some respite from feeling different (22). Accessing the support offered by friends and family can also reduce stress (24) and help cope with the challenges that living with a chronic condition can raise (25).

Most girls in the study reported pain, disability and fatigue; largely absent in accounts from boys, although fatigue was discussed by a minority. This novel finding is of interest and complements our previous data in adults with SRS where we found that adult women's experience of SRS was one of pain, fatigue, and disability, a phenomenon little documented

in existing literature(6). Although approximately a third of adolescents in Europe experience fatigue (26-28), it may be more significant in individuals with SRS because of their tendency to low lean mass(6). Our findings require verification in other cohorts and further study regarding the causative mechanisms of pain and disability among girls/women living with SRS.

Participants reported being treated differently due to their appearance and wanting to change the way they looked in order to fit in. These findings again echo those from our adult study, where adults reported difficulties in adolescence forming romantic relationships that, for some, persisted into adulthood. However, adolescent participants did not report present or anticipated issues with dating, although participants may have hesitated to discuss such sensitive topics with the interviewer, as suggested by one young person who declined to comment on the topic. Previous research has found that having a visible difference does not appear to prevent adolescents from embarking on romantic relationships, but many experienced concern about future relationships or current relationships progressing(29). Future research should include the exploration of romantic relationships in relation to visible differences for people living with SRS.

[Figure 3. Here]

Currently, clinical management of SRS focuses on height optimisation, but our data show that appearance-related concerns and psychosocial issues require at least equal attention. This study, which complements our adult findings, demonstrates enduring issues for people living with SRS and gives rise to specific recommendations for professionals working with this group (Figure 3). Support for children and adolescents should include: increased understanding of psychosocial issues among clinicians, teachers and family members; access to psychological

support for appearance-related concerns, manage pain and fatigue(30); peer support(31); career advice sensitive to concerns regarding living with a health condition; and guidance on diet and exercise, especially after GH treatment stops(17), as people with SRS may be at risk of metabolic problems in adulthood(14). When implementing these recommendations it is important to highlight that severity of condition (32, 33) or visible difference (34) is not related to psychological distress.

Strengths, limitations & future directions

Our study had several limitations. Firstly, our sample was small and lacked diversity (e.g. gender, ethnicity, culture) though this was unavoidable due to the rarity of SRS and difficulties in recruitment of adolescents(35). However, as our adolescent data and adult reports of adolescence are similar (i.e. pain, disability, feeling different, anticipated stigma and resilience), the current study adds weight to our adult findings. Moreover, as our study involved a specific, rare and previously undescribed experience, a smaller number of participants was acceptable due to higher information power.(36) Secondly, we suspect our findings regarding more sensitive topics, such as dating and mental health issues, may not represent the full picture for adolescents living with SRS.

Conclusion

Adolescents with SRS may experience psychosocial difficulties related to feeling and looking different; pain, disability, and fatigue; anticipated stigma and future challenges around employment. Unlike conditions such as Turner's syndrome that have medical issues monitored into adulthood, adolescents living with SRS are discharged from healthcare at a pivotal time when they require the most psychosocial support. Clinicians involved in the care

of adolescents with SRS should be aware of the experiences highlighted here to support their patients now and prepare them for the future when discharged from the specialist service. Without such guidance, people living with SRS risk biopsychosocial problems that could be ameliorated with appropriate prevention and/or treatment interventions.

ETHICAL APPROVAL

Ethical approval for the study was granted by the NHS Research Ethics Committee South Central – Hampshire B (REC reference: 13/SC/0630).

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CONFLICT OF INTEREST STATEMENTS

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CONTRIBUTORSHIP STATEMENT

All authors made the following contribution:
Substantial contributions to the conception or design of the work, or the acquisition, analysis or interpretation of data.
Drafting the work or revising it critically for important intellectual content.
Final approval of the version published.
Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

What is already known on this topic

- The clinical management of Silver-Russell syndrome (SRS) during childhood has a major focus on optimising height.
- Psychosocial evaluation is not routinely offered to children and adolescents in clinics.
- Appearance-related concerns result in psychological distress for some individuals living with SRS.

What this study adds

- Aspects of the lived experience, such as pain, disability, feeling different, anticipated stigma and resilience, are similar in adolescents and adults living with SRS.
- Pain is a key symptom for girls with SRS, currently undocumented in existing literature. The causes and management of pain requires further investigation.
- Health professionals and families need to offer psychosocial support at key stages of development in adolescents as they prepare to be discharge to adult services.

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FIGURES

[1]O'Reilly, M. and N. Parker, *Doing Mental Health Research with Children and Adolescents: A Guide to Qualitative Mehtods*. 2014, London: Sage. [2]Cameron, H., *Asking the tough questions: A guide to ethical practice in interviewing young children.* Early Child Development and Care, 2005. **175**(3): p. 380-390. [3]Morse, J.M., *Ethics in action: ethical principles for doing qualitative health research.* Qualitative Health Research, 2007. **37**: p. 1003–1005. [4]Duncan, R.E., et al., Is my mum going to hear this? Methodological and ethical challenges in qualitative health research with young people. Soc Sci Med, 2009. 69(11): p. 1691-9.

Figure 1. Considerations when interviewing adolescents.

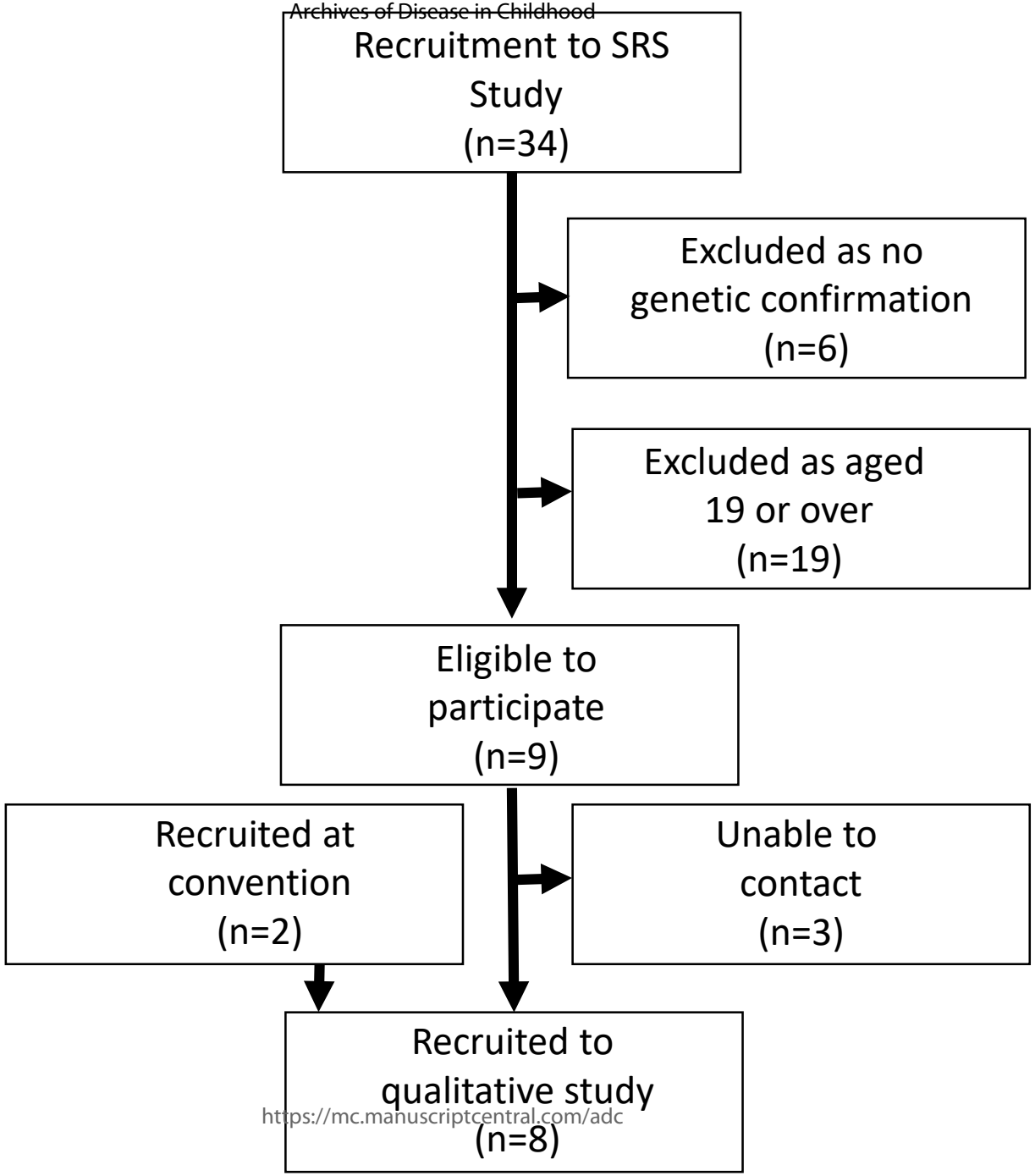
Figure 2. Source of recruitment to qualitative study.[2]

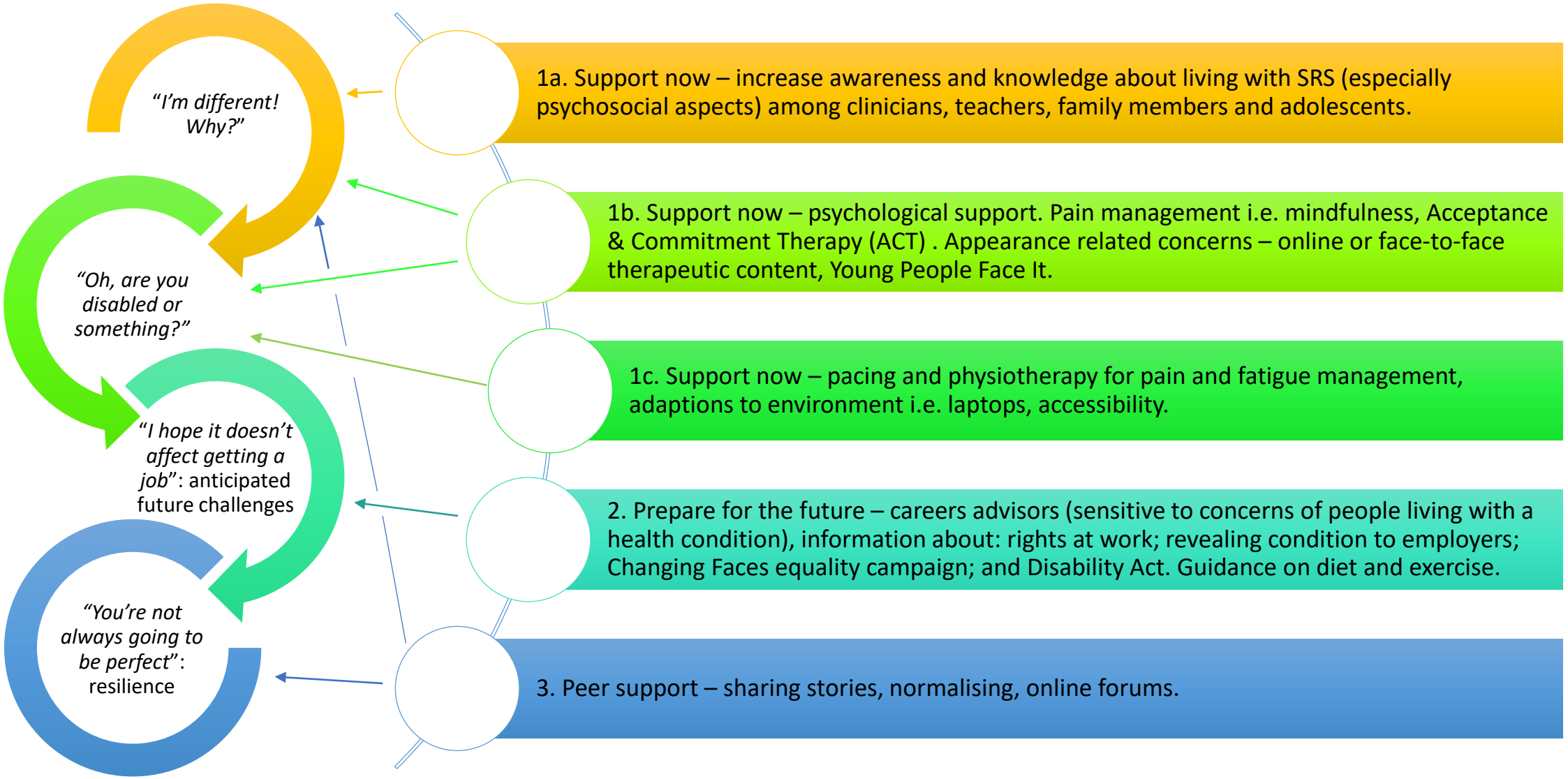
[2] Recruitment of 37 participants was from a larger study. Recruitment to the current study focused on those aged 18-years or younger.

Figure 3. Recommendations by theme.

Considerations when interviewing adolescents	Interviews were shorter depending on the young person's age and attention span[1]
	Adolescents may not be familiar with giving their views or discussing their experiences[2]
	Adolescents may be used to a more academic environment, so more acquainted with there being a 'right' answer[1]
	Qualitative research methods may pose a risk to participants as it often involves revealing intimate details about themselves and their lives, which may become an issue for more vulnerable participants who are young or have learning difficulties[3]
	Adolescents have less life experience so may not be as well equipped to anticipate and deal with an interview scenario, they may be less assertive and may lack confidence[4]

[1]O'Reilly, M. and N. Parker, *Doing Mental Health Research with Children and Adolescents: A Guide to Qualitative Mehtods*. 2014, London: Sage. [2]Cameron, H., *Asking the tough questions: A guide to ethical practice in interviewing young children.* Early Child Development and Care, 2005. **175**(3): p. 380-390. [3]Morse, J.M., *Ethics in action: ethical principles for doing qualitative health research.* Qualitative Health Research, 2007. **37**: p. 1003–1005. [4]Duncan, R.E., et al., Is my mum going to hear this? Methodological and ethical challenges in qualitative health research with young people. Soc Sci Med, 2009. 69(11): p. 1691-9.




"I'm different! Why?"
"Oh, are you disabled or something?"
"I hope it doesn't affect getting a job": anticipated future challenges
"You're not always going to be perfect": resilience
1a. Support now – increase awareness and knowledge about living with SRS (especially psychosocial aspects) among clinicians, teachers, family members and adolescents.
1b. Support now – psychological support. Pain management i.e. mindfulness, Acceptance & Commitment Therapy (ACT) . Appearance related concerns – online or face-to-face therapeutic content, Young People Face It.
1c. Support now – pacing and physiotherapy for pain and fatigue management, adaptions to environment i.e. laptops, accessibility.
2. Prepare for the future – careers advisors (sensitive to concerns of people living with a health condition), information about: rights at work; revealing condition to employers; Changing Faces equality campaign; and Disability Act. Guidance on diet and exercise.
3. Peer support – sharing stories, normalising, online forums.