

The challenges of recruiting adolescents for appearance-related research in a specialist tertiary hospital

VIEWPOINT

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Aim: To discuss the experiences and specific challenges of recruiting adolescents with appearance-altering conditions or injuries for qualitative interviews exploring appearance worry and an acceptability study testing a new online intervention designed to target appearance-related distress.

Methods: Between August 2016 and January 2017, 88 families were invited to take part in the studies. Patients were approached in outpatient consultations at Australia's largest paediatric tertiary hospital. A final 25 participants were recruited to at least one of the studies.

Results: Successfully recruiting adolescents for research that explored appearance worry was challenging. Environmental barriers in the clinic environment and reluctance discussing appearance-related subject matter impacted clinical staff involvement and participant engagement. Misconceptions about resolving and managing appearance distress also influenced consent.

Conclusions: This paper illustrates the complexities of recruiting young people for appearance-based research in a paediatric tertiary hospital and important considerations for successful recruitment. Recommendations highlight the importance of early participant involvement, maximising the support of clinicians with study-specific training, being mindful of first impressions and adopting novel, non-traditional methodology and advertising strategies. Knowledge gained from this paper aims to assist future researchers conduct more successful appearance-based research in paediatric tertiary centres.

Introduction

Conducting research with adolescents living with appearance-altering conditions or injuries is a growing area. Current literature highlights the psychosocial consequences of living with an altered appearance and the lack of high quality evidence-based interventions¹. With up to one-third of those living with an altered appearance struggling with issues such as socialising, self-confidence or body image², engagement in appearance research can be confronting. Recruitment is further complicated when participants are patients from a tertiary hospital as there are additional environmental factors to consider. Currently, there is a dearth of literature that discusses the challenges of conducting appearance-related research. This article discusses the experiences of recruiting adolescents for research that explored the psychosocial consequences of living with a condition or injury that alters appearance. The paper discusses complexities associated with conducting appearance-based research in a paediatric tertiary hospital and offer recommendations. The authors emphasise the importance of patient involvement, sensitivity and privacy eliciting appearance discussion and utilising creative, non-traditional methodology when designing appearance projects.

Methods

Study Design

The research involved two studies: 1) Qualitative interviews exploring the psychosocial impact of living with a condition or injury that alters appearance and 2) Acceptability testing of a new online intervention designed to target appearance-related distress. Qualitative semi-structured interviews explored gaps and barriers in appearance-related care, experiences and preferences for support to treat the psychosocial consequences of an altered appearance. The acceptability study tested the cultural suitability of a British online psychosocial intervention³ that combines cognitive behavioural therapy and social skills training to target appearance-related distress. Adolescents were given access to the website for at least two weeks, followed by a semi-structured interview that explored the intervention's acceptability to Australian users. Interviews were audio recorded, conducted face to face or online (e.g. Skype) and lasted at least 40 minutes. Interviews were conducted by a female chief investigator (CI), transcribed verbatim and coded by at least two independent coders. Qualitative interview data was analysed using thematic analysis and acceptability data was analysed using content analysis.

Participants

Thirty-six adolescents consented to at least one of the studies. A final 25 participants (N=14 for qualitative interviews and N=11 for acceptability study) were recruited. Adolescents aged between 12 and 17 ($M = 15.12$, $SD = 1.54$, 22 Females and 3 Males) were purposively recruited from specialities including paediatric surgery, burns, plastics and reconstructive, vascular malformations, epidermolysis bullosa and maxillofacial from Australia's largest specialist paediatric hospital. The CI approached patients face to face at outpatient consultations. Participants were eligible if they self-reported appearance worry or were subject to appearance-related bullying.

Results and Discussion: The Challenges

Clinic environment

Governance, ethics, access to participants, gatekeepers and a predominant biomedical culture heavily impact on the success of children's health research in hospitals⁴. Conducting appearance research in a paediatric hospital is further complicated by environmental challenges within the clinic setting. In addition to their aesthetic differences, a large proportion of eligible recruits were experiencing physical and/or medical complications. Therefore, most patients fell under multiple specialist teams and were required to attend multidisciplinary clinics. As the recruitment site was a tertiary centre, it was not uncommon to see ten or more staff and students present during a consultation. Whilst some teams had specialists rotate in and out, other departments had families seated at the front of a room, facing the "institutional gaze"⁵ of multiple clinicians. Although staff commented this was an efficient way to make collaborative care decisions, being on 'display' was overwhelming for patients. Families made comments, such as 'wow, there's a lot of people in here' and adolescents often sat still, avoiding eye contact and discussion with clinical staff. For a population that commonly experiences stigmatisation and staring due to looking 'different'⁶, the clinic atmosphere appeared to generate additional anxiety and self-consciousness for patients. This created challenges for recruitment as patients were often experiencing high anxiety prior to being approached. Recruiting primarily through outpatient clinics was a balancing act. Avoiding further anxiety to patients and ensuring minimal disruption to clinical care was crucial. As most departments had little research integrated into routine care, timing recruitment was complex. One of the main obstacles of recruiting within clinics was the limited opportunity to provide a private space to discuss appearance subject matter.

Staff avoid appearance talk

During consultations, it was evident that appearance subject matter was not openly discussed. The exception was the offer of surgical intervention to improve aesthetic concerns. Whilst it is not unusual for hospitals to prioritise medical care⁴, it was evident that psychosocial issues were rarely explored, particularly the emotional and social impact of aesthetic differences. Despite many staff attending consultations, there was also a lack of psychosocial specialists such as social workers or psychologists present. Conversations with staff supported these observations. They raised concerns about limited psychosocial staffing and their own lack of confidence to manage appearance psychosocial issues. Clinicians reported fear to delve into appearance issues due to feeling underqualified or having poor awareness of support to offer. This was a specific challenge for this research as successful recruitment relies on the support of clinicians in hospital settings⁷. For this project, the CI was not a member of any of the clinical teams. Despite the lack of rapport, the CI would have to initiate appearance conversation with families. This impacted recruitment as some caregivers disclosed that their child may not feel comfortable discussing their appearance worry with an unfamiliar person. Although most clinicians expressed enthusiasm for the studies, their lack of confidence and limited capacity to devote to the research meant it took longer for the CI to secure informed consent.

The ‘sensitivity’ of appearance

This research was deemed ‘sensitive’ due to utilising qualitative methodology and the perceived vulnerability of the target population⁸. Adding further sensitivity was its focus on ‘appearance worry’. When initially approached, the majority of caregivers reported that this had been the first time someone had asked them about their child’s appearance. Despite many families being engaged with the hospital since their child was young, parents often discussed that the focus of their child’s care was their next surgery or functional needs. Many parents did report that living with an altered appearance had either been a past or current psychosocial concern for their child, but none or little support had ever been offered via secondary care. If they had accessed support, it was sought through school or a local support group. However, this support was often limited and not appearance specific, highlighting the dearth of specialist support available across primary, secondary and community settings. Although these comments supported the goals of the research and justified its’ clinical relevance, some caregivers were hesitant in committing to the research due to its sensitive nature.

The idea of exploring appearance worry was overwhelming and anxiety provoking for families. Some parents, who identified that their child had current or previous psychosocial

issues related to their appearance declined due to concerns about ‘exacerbating worry’ or ‘introducing the idea of appearance worry’. In these cases, parents may have wanted to protect their children, due to fears of upsetting them⁹. Being reminded of having a condition or injury that causes ‘difference’ was also a concern. One parent explained that she had never discussed appearance with her daughter because she did not want to highlight that she was different. Some adolescents also queried why they had been approached, expressing ‘do I look different to you?’ These interactions highlight how important it is for clinicians and researchers to be aware of the sensitivity of appearance research. For a population that commonly struggles with being stigmatised for the way they look¹⁰, reminding eligible patients that they are ‘different’ or their appearance is the basis of eligibility can impact on recruitment¹¹.

The topic of appearance worry was reported as a reason for some families to need more time to consider participation. This was to ensure the child was comfortable or to consult with another parent. This was a frequent request from families over recruitment and made follow-up difficult. In some instances, parents reported the desire for their child to participate to ‘help others’ or ‘help them with their worries’, but the adolescent declined. In contrast, some young people expressed a desire to participate but the parent declined. After direct recommendations from clinical staff, the CI also approached patients who had previously disclosed psychosocial concerns to their clinical teams. Despite this, some parents were quick to decline on behalf of her child. Dealing with parental gatekeepers is a common challenge when recruiting young people⁹ and understanding the parent-child relationship is crucial¹¹. For this research, parents may have wanted to protect their child from perceived ‘harm’⁹ or adolescents might have been reluctant to be involved if they believed their appearance worries would be disclosed to their caregivers¹².

Appearance misconceptions

Unfortunately, it was difficult to recruit males for this research. This is despite increasing evidence that males are just as vulnerable to poor body image as females¹³. Body image dissatisfaction among boys can be more complex and difficult to identify than for girls¹⁴, partly because it can be more challenging or less socially acceptable for them to discuss¹⁵. Males often reported to the CI that they ‘didn’t care’ or ‘worry’ about their appearance. Interestingly, many parents of males dismissed or downplayed their son’s appearance as ‘just a scar’. We believe this influenced recruitment as some of the males approached may have felt uncomfortable challenging their parent’s perception of their psychosocial adjustment. Due to

ethical requirements, both a parent and their child were required to provide consent and assent for these studies. Therefore, capturing males in this recruitment was challenging as it was sometimes difficult to gauge a true indication of the patient's adjustment without parental involvement.

Another misconception that potentially impacted recruitment was the prevailing myth that surgery can resolve appearance worry¹⁶. This was evidenced by the refusal by a grandmother who felt the research was irrelevant as '[her granddaughter] was going to have surgery soon, and she'll be all fixed up'. While medical efforts can attempt to correct aesthetic differences, there can be delays (e.g. due to developmental factors) and there are often limitations to how much a surgeon can change. Unfortunately this is a difficult myth to debunk as many adolescents and their families find it difficult to understand the limitations of surgery, and as a result, can be disappointed with surgical outcomes.

Avoidance is a common strategy adopted by patients with appearance-altering conditions or injuries to deal with negative social experiences¹⁷. Commonly, patients believe that they can reduce anxiety provoking situations by removing themselves¹⁸. However, avoidant behaviour can often lead to social isolation which impacts a patient's quality of life¹⁹. Interestingly, parental avoidance was observed during recruitment and possibly hindered research involvement. This was evidenced in a patient who had been bullied at school for six years due to his condition. The caregiver reported that the teasing had impacted her son so significantly that he styled his hair a certain way to avoid attention from peers. Despite believing the value in the research, the parent declined because she had decided to home school him to eliminate the effects of bullying. In this case, the parent assumed that the research was not necessary as taking her son out of school would eliminate the teasing he had been struggling with.

Recommendations

Recruiting adolescent patients within paediatric hospital settings can be challenging. An added complication, is when the research explores a sensitive topic such as appearance. The clinic atmosphere, difficulties in eliciting appearance talk and wavering perceptions of appearance-related subject matter can create obstacles in recruitment for appearance-based projects. Lessons learnt from this recruitment has led to recommendations to be considered by future appearance researchers in paediatric tertiary settings:

- Patient involvement is crucial. Throughout the research process, consult with an advisory group of patients and their caregivers (e.g. INVOLVE²⁰). Drawing on patient knowledge and experience can break down power relations between non-affected researchers and their target population and empower patients. Invite participants to make comments on their interview transcripts or give feedback on recruitment approaches. Offer to send final results upon completion.
- Pre-empt potential recruits. Send a letter or email outlining the research prior to clinic appointments. Awareness prior to being approached can facilitate more openness to participation.
- Approach potential recruits prior to specialist clinics. This avoids attention on the patient's appearance in a large group setting and minimises the patient feeling 'on display'.
- Discuss research in a private room. This offers families more privacy and comfort to consider participation.
- Give eligible recruits time to consider participation. Families may not feel comfortable saying yes immediately. Obtain verbal consent to follow up over the phone or via email within one week of initial meeting.
- Advocate for research recommendations from clinicians. This facilitates a better response rate from families. Clinicians often have an established level of rapport and families place a high level of trust in medical opinion.
- Maximise the support of clinicians. Spend time educating clinicians about initiating appearance discussion by conducting study-specific training prior to recruitment.
- First impressions count. Carefully consider wording and phrasing in appearance talk. This applies to staff training, participation information sheets, advertising and approaching patients in person.
 - Avoid medical terminology like 'disfigurement', 'deformity', 'defect' or 'abnormality' and do not refer to a patient's 'difference' or being 'different'. More sensitive wording such as 'altered appearance' or asking patients how their condition affects their 'body confidence' is recommended.
 - Validating appearance-related psychosocial concerns is important. Dismissing appearance worry should be avoided. Often patients feel alone and isolated so downplaying their worry is unhelpful.
 - Do not label patients by their condition or injury or pathologise their symptoms. Avoid phrases such as 'victim of...' or 'suffers from' and replace with 'the patient

has a...(e.g. burn)²¹. Being objective and factual reduces negative connotations and value judgements. Pitch sensitive research positively by emphasising the benefits and value of the project.

- Incorporate creative, non-traditional methodology. Utilising arts-based methods (e.g. photography) has been highly successful in the authors' follow up project. Photography gives participants control over their involvement and aids discussion of sensitive issues¹⁵. Offering online options is helpful for reaching rural and regional participants and anonymous platforms may increase participant's confidence to discuss sensitive issues.
- Create a support plan to counteract concerns raised by research involvement. This can ease clinician and caregivers' apprehension about exacerbating worry or discussing sensitive topics.
- Adopt multiple recruitment strategies. Relying on outpatient consultations is time consuming and overwhelming for patients. Maximise reach through social media (e.g. Facebook, Instagram, Twitter). Facebook has been found to be more efficient in recruiting hard to reach populations when compared with traditional strategies²². Make the most of advertising by utilising hospital media and communication departments, newsletters and email networks.

Conclusion

Recruiting adolescents for appearance research is complex. Clinic environments and hesitancy discussing appearance-subject matter complicate appearance research in paediatric tertiary settings. Promoting patient involvement, study-specific training and incorporating creative non-traditional design and methodology can aid facilitation and participation in sensitive research topics. Flexibility and sensitivity are required by the research team to improve the participation and retention of adolescents in appearance research.

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