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# “I'd Like to Have More of a Say Because it's my Body”: Adolescents’ Perceptions around Barriers and Facilitators to Shared Decision-Making

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**Abbreviations:**

SDM: Shared decision-making

HCP: Healthcare professional

LTC: Long-term condition

## Abstract

**Purpose**

Adolescents living with long-term conditions (LTCs) often feel as though they are left out of discussions and decisions with healthcare professionals, which can give them the impression that their views are not important. Research around decision-making during clinical encounters often fails to represent adolescents' perspectives. This study explores adolescents' perceptions and experiences, focusing on identifying the perceived barriers to, and facilitators for, their involvement in shared decision-making.

**Methods**

Nineteen adolescents (13-19 years) with LTCs were recruited from endocrinology, rheumatology, neurology and nephrology clinics. Participatory qualitative interviews were conducted using life grids and pie charts, and transcripts were analysed thematically.

**Results**

Four overarching themes and nine sub-themes were identified which describe barriers and facilitators around shared decision-making. Adolescents need to feel as though their involvement is supported by parents and healthcare professionals, that their contribution to the decision-making process is important, and will yield a positive outcome. Adolescents often feel it is their right to be involved in decisions that affect them, but also feel as though the adults' contributions to the decisions are considered more valuable. Adolescents need to feel capable of being involved, in terms of being able to understand and process information about the available options, and ask appropriate questions.

**Conclusions**

This work highlights a number of ways shared decision-making can be facilitated between healthcare practitioners and adolescents with LTCs. Identifying the needs of adolescents with LTCs is necessary for optimising the SDM process and to support them during healthcare consultations.

**Keywords:** Adolescent; Shared Decision-Making; Long-term condition; Qualitative Methods; Chronic Care, Patient-Centred Care

## 1.0 Implications and Contributions

Adolescents describe a number of barriers and enablers around their involvement in shared decision-making. These include having favourable context, positive evaluation, feeling able and ready, and having some sense of actual control alongside their developing identity and perceptions of what is ‘normal’. The findings will assist in development of interventions aimed at improving SDM with this population through identification of components that are necessary, feasible and salient.

Adolescents with long term conditions (LTCs) often feel as though they are left out of discussions and decisions with Healthcare Professionals (HCPs), which can give them the impression that their views are not important (1). Current recommendations emphasise the importance of involving adolescents in healthcare decisions, and state that health service provision should be a partnership between the HCPs, young persons and their families (2, 3). Moreover, patient involvement in decision-making has been identified as a key indicator of adolescent healthcare quality (4). Shared decision-making (SDM) has the potential to allow adolescents with LTCs to evaluate the benefits and risks of various healthcare options, while enabling a shared understanding of preferences and possible issues, such as difficulties performing self-management tasks or managing side-effects (5, 6). SDM may increase adherence to self-management plans (7, 8), which can be particularly important during adolescence when self-management and health outcomes of patients with LTCs have been found to decline (9-11). In addition, adolescent involvement in healthcare decisions is associated with a better understanding of their health condition and treatment (12).

Nevertheless, SDM does not occur consistently in clinical encounters, and adolescents with LTCs often act as bystanders (13, 14). Furthermore, previous literature examining these encounters often focus on parents' and HCPs' experiences, omitting the young person's narrative (1, 15). Therefore, the purpose of this study is to explore adolescents' perceptions and experiences, focusing on identifying the perceived barriers to, and facilitators for, their involvement in SDM.

## 2.0 Methods

### 2.1 Participants and Recruitment

A sample of nineteen adolescents between the ages of 13 and 19 (mean + SD = 16 ± 1.9) years was recruited from young adult (transitional) or paediatric neurology, endocrinology, nephrology or rheumatology clinics in South Wales (Table 1). Patients attending these clinics tend to have long-term conditions which have distinct characteristics from one another. However, the conditions often persist into adulthood, affect the patients' lives substantially, and have a range of management options, allowing for the ideal environment for SDM. Potential participants were purposefully identified by members of their clinical team, and approached in attempt to obtain an even distribution of ages, genders and LTCs. Information packs were distributed to eligible adolescents containing details on how to respond if interested in participating in the study, to which 29% responded. Participants provided informed consent and parental consent was obtained for participants under 16 years. Interviews took place either at University Hospital Wales, the participants' homes or a quiet café, away from any other customers or employees. Parents requested to be present during the interviews on two occasions. Respondents received a £20 voucher as a token of appreciation for their participation. Ethical approval was obtained from the NHS Research Ethics Committee and Cardiff and Vale University Health Board Research and Development Office.

### 2.2 Participatory Interviews

Participatory interviews were conducted by the first author (AJ), an experienced researcher trained in qualitative methods, to explore the adolescents' narratives in order to identify possible barriers and facilitators to SDM. Respondents were first asked to complete a life grid (16) with important events surrounding their health condition and doctors' visits. Participants were asked to describe the events in the grid, and prompted to expand on the events by the interviewer asking questions. Where healthcare decisions were mentioned, participants were asked to complete pie charts (17) indicating both the real and desired roles of those involved in the decisions (Figure 1, Table 2). Possible reasons for discrepancies between the real and desired roles were explored. A follow-up semi-structured interview schedule was also derived from the findings of our systematic review (1) (Table 3). Data collection methods were piloted with two male adolescents.

### 2.3 Qualitative Analysis

Interviews were audio recorded and transcribed (AJ). We then conducted a thematic analysis using Braun and Clarke's (18) approach. By following the six phases of coding and theme development, we developed four themes in response to our aims. This process involved the first author repeatedly reading the transcripts, and coding the entire data set, which resulted in a demarcation of common themes. Provisional themes were reviewed and discussed by two authors (AJ and NJW), and further refinement of the coding and analysis was undertaken until the salient patterns repeated across and within transcripts were identified and agreed on (18). Initial coding and theme development began after the first fourteen interviews. The five subsequent interviews were coded, and no new themes were identified. It was therefore determined that inductive thematic saturation had been achieved (19). Another author (DH) then double coded 10% of the transcripts, and the outcome of proceeding discussions resulted in modification of sub-theme names, and an additional sub-theme. Pseudonyms were used, and potentially identifying minor details were changed for confidentiality purposes. Data were managed using NVivo 11 qualitative data analysis software (20).

## 3.0 Results:

Interviews ranged from 20:04 to 57:25 (Mean+ SD =35:35± 10:06, Median =34:31) minutes. Some participants freely provided detailed information using the life grid, whereas others were more hesitant, even with prompting. The presence of parents in the room (n=2) did not appear to affect the participants' willingness to disclose. Themes identified from the interviews were not found to be distinct between genders, ages or LTCs.

Many participants were able to identify explicit barriers to and/or facilitators of their involvement in SDM. They also discussed such influences more implicitly when describing their experiences with decision-making during consultations. Our analytic review process resulted in a final analytic structure of four themes and nine subthemes which describe barriers and facilitators around SDM (Table 4). The quotations used to illustrate the themes are followed by participant gender, age, clinic recruited, and elapsed time since their diagnosis.

## 3.1 *Interactional dynamics within the triadic relationship*

The dynamics between the adolescents, parents and HCPs strongly influence adolescent involvement in SDM.

### 3.1.1 HCPs communication approach

The way HCPs communicate with parents and the adolescents can either endorse or dismiss adolescent involvement in the decision-making process. Clinicians' behaviour that invites and encourages involvement includes asking and inviting questions; speaking directly to the adolescents instead of the parents; information provision, including presenting treatment options; and providing adolescents with enough time to consider the options so that they do not feel rushed. Adolescents feel more comfortable when HCPs communicate in a manner that is perceived as friendly, which can encourage involvement.

"*Sometimes it helps when the doctors are like nicer. Like when the doctors are friendly and stuff, then you feel more at ease to talk to them.  Whereas if it just feels like they're bored or like, they're like really serious, it's kind of like hard to speak"* (Female, aged 19 , endocrinology, 6 years).

Adolescents, even those who believe they play a large role in decision-making, report being provided insufficient information surrounding treatment options, which limits their ability to be involved. Some adolescents feel that HCPs are too busy to explain their condition or treatment options in detail.

"*I don't feel like I've had it properly explained by the doctor, cuz obviously you've got time slots cuz more people need to come and see. They can't spend all day telling you about it*." (Male, aged 18, endocrinology, 5 years)

### 3.1.2 Parental support of adolescent involvement

Participants often feel that their parents' roles in decision-making should be smaller than they actually are, and that parents should play more of a supporting role.

*"They* [parents] *should just like advise me mostly, because I know it's about me"* (Female, aged 14, rheumatology, 3 years)

Parents can support involvement by filling in missed gaps of information provided by adolescents, and helping adolescents to process and remember information provided by HCPs. However, adolescents often feel their parent(s) limit their involvement by not allowing them the opportunity to speak.

*"My mother takes over, because she thinks she can have more of a say than I do cos s she's the mother…..she should just stand back and let me talk, say in my opinion."* (Female, aged 18, nephrology, 18 years)

Having parents present in the consultation can sometimes cause unwillingness to share certain information of a sensitive nature.

*"No offence to any parents, but having the parents out of the room is a massive relief because it just is, and if you feel confident enough to talk about it"* (Female, aged 15 endocrinology, 7 years)

### 3.1.3 Power imbalance

Adolescents mostly would like a nearly even three-way split between themselves, parents and HCPs, usually allocating slightly less of a say to parents. However, the adults (parents and HCPs) are often seen as having more influence over the decision-making process, and that their contribution may be more valuable. The perceived power imbalance between the adolescent and the adults can cause adolescents to feel that the others have, and possibly should have more authority over decisions.

*“They [HCPs] are generally just talking to the adults, looking at the adults and not me….. I know why they do it mostly cuz, you know, they’re adults, they get the most attention really”* (Female, aged 14, rheumatology, 3 years)

This can cause adolescents to feel as though they are not “allowed” to be involved in the decision-making. Furthermore, consultations are sometimes viewed as a time when adolescents are reprimanded by adults for less favourable self-management results, such as high HbA1c levels, which can cause feelings of guilt and reluctance to engage.

## 3. 2 *Expression of autonomy*

Overall, adolescents with LTCs react positively towards the concept of SDM. They value and want a sense of control over their lives, and decisions that affect them.

### 3.2.1 Sense of agency

Adolescents express ownership over their bodies and their health. They often feel that they should be involved, and that it is their right to be included in the decision-making process, which facilitates SDM.

*“Um I think you should be allowed to make any decision you want really.  Because it's you as a person, it’s not them, they’re not going through it”* (Female, aged 16, neurology, for 5 years)

Adolescents state that they know about their own lives and bodies better than anyone else, and therefore feel that it is vital that they have a say in decisions which are relevant to them. However, many adolescents acknowledge that they are not, and have not been as involved in the decision-making process as they should be.

*"I dunno, I suppose it's my body, and I have to deal with the consequences so I should probably have more of a say"* (Male, aged 17, endocrinology, 2 years)

### 3.2.2 Sense of empowerment

When adolescents feel they have control over what is happening to them, they react positively towards being involved in discussions and decisions, which can facilitate SDM.

*"I really felt like I was being in control of myself then. And I could give my opinion on what was going on"* (Female, aged 15, neurology, 6 years)

On the other hand, a number of adolescents spoke of their reactions to feelings of powerlessness and perceived loss of control. This can lead them to refusing to engage in discussions, sometimes taking complete control over a decision as a consequence.

"*when I come off medication for like a year, that was all my own decision, and they* [HCPs and parents] *didn't really have an option, I didn't let them have an option cuz I was like 'no I don't wanna be on that' I just like refused it*" (Female, aged 18, neurology, 15 years)

Reports of autonomous decision-making on the part of the adolescent were the only decisions for which participants indicated that they should have had a smaller role.

## 3.3 *Belief around own ability and value of contribution*

This theme focuses on adolescents' evaluation of their involvement in different aspects of SDM. The concept of a "good" or "right" decision often arose in discussion.

### 3.3.1 Perceptions around involvement outcomes

Treatment preferences and values vary between individuals. Some adolescents identify the importance of adding their input to discussions and decisions in order to find the treatment that best suits them, and to best understand what is happening to them.

*"I think if I was more involved in the decision, I could take more ownership over my self-management." (Male, aged 17, nephrology, 2 years)*

However, adolescents do not always acknowledge the importance or benefits of their contribution. They may not feel interested or motivated to be involved, and often believe that the doctors hold the knowledge about what is best for them.

"*You just really, just have to go along with [treatment] because the doctor's right, end of story really."*(Male, aged 19, nephrology, 10 years)

### 3.3.2. Perceived adequacy of own knowledge and skills

Participants spoke about self-efficacy regarding a number of aspects of involvement; including their knowledge and understanding of their condition and management options; asking questions; remembering information; discussion involvement; and making a "good" decision. Insufficient understanding surrounding their condition and treatment options is the most commonly mentioned barrier to SDM. There was no apparent relationship between self-efficacy and participants' age at the time of interview, however, many expressed that their confidence increased as they gained more experience living with their condition, which allowed them to become more involved in discussions and decision-making.

"*I dunno, I think just cuz I'm older, and at the time I didn't really know very much about diabetes, so I kind of didn't feel like I could say what I wanted cuz I didn't want it to be like a little bit wrong or something silly, if that makes sense. Now I feel just a* *little bit more confident because like obviously I've had it for years, so I kind of do know."* (Female, aged 19, endocrinology, 6 years)

Fear of saying something "wrong" or asking a "stupid" question is a common sentiment, which prevents adolescents from being involved.

*"Sometimes I don't understand what's going on, but I feel like if I ask a question, I might sound kind of stupid, um they're like kind of basic questions, you know like normal questions, yeah stuff like that. Maybe I shouldn't ask them because they're too basic"* (Female, aged 15 with epilepsy for 6 years).

Perceived capability in their ability to remember, both what to say and what has been said also influences involvement.

"*My memory is horrendous. I prefer my mum to say it so I don't miss anything out."* (Female, aged 16, neurology, 6 years).

## *3.4 Navigating personhood and patienthood identities*

This theme represents the conflict of identity between patient versus self that adolescents with LTCs can experience. This conflict can cause them to go between accepting their LTC and disconnecting from or avoiding the fact that they have the condition. This can lead to disengagement from healthcare discussions and decisions.

### 3.4.1 Endeavour for normality

The importance of trying to maintain as normal a life as possible was highlighted by many of the adolescents in the interviews. Adolescents often compare their current lives to before diagnosis, and strive to regain that sense of normality.  Some adolescents acknowledge that involvement in decision-making can assist with the selection of a treatment plan which helps them to regain normality, such as changing from insulin injections to an insulin pump. Feeling as though they can be “normal” teenagers alongside their LTC can result in acceptance of the condition, and allows them to engage and be involved in SDM. However, adolescents might not want to be involved in discussions and decisions during consultations because they prefer not to be reminded of having a condition which sets them apart from others. Having contact with other adolescents with LTCs can help adolescents maintain feelings of normalcy:

“*If you’re meeting people who have got similar health conditions to you, or experience health conditions in general, you can get out with them, you can talk with them, see how they're feeling, what they've experienced, and I think that's a really good way to also influence you to um, you know, talk about your decisions because you know then what other people have done, and what they've been through, knowing that you're not alone.”* (Female, aged 18, nephrology, 2 years).

### 3.4.4 Readiness to be involved

At the time of diagnosis, adolescents can find it difficult to process information, and prefer less involvement.

*“you’re shocked cuz you’ve obviously just been diagnosed and then it’s hard to take in so much information because it just feels like it’s been like forced on you, obviously you’ve gotta learn it, but there’s just a lot to take in at that time…..now I feel just a little bit more confident because like obviously I’ve had it for years (Female, aged 15, endocrinology, 1 year)*

Apart from at diagnosis, all adolescents express a desire to be involved in decisions to some extent. Acceptance of their condition is necessary for adolescents to feel ready, and is more likely to be reached as they gain more experience living with the condition. Adolescents need to feel emotionally ready to receive certain information and be involved in certain discussions and decisions. Involvement when adolescents do not feel ready can lead to avoidance and fearfulness.

*“I dunno, I just got too nervous when they were talking about it….. and didn't want to think about it”* (Female, aged 15, nephrology, 13 years)

## 4.0 Discussion

This study provides insight into adolescents’ perceptions around decision-making involvement by focusing on their lived experiences during consultations. The use of pie charts is a method that has been employed successfully in previous studies exploring adolescents’ roles and preferences in the decision-making process (17, 21). However, this study differs in its focus on possible reasons for the discrepancies between the real and desired roles, and potential enablers of involvement.

Adolescent-reported barriers and facilitators to SDM relate to interactional influences, and evaluations around SDM in line with their self-efficacy and sense of self. Our results add to the growing evidence base identifying the significance of the relationship between the HCP and adolescent patient, and the importance of reducing the perceived power imbalance (22, 23). This is also a known barrier to SDM in adult populations in long-term care, and patients often undervalue the contribution of their own personal preferences to decision-making, rather than that of HCPs technical knowledge (24, 25). In paediatrics, the triadic relationship adds an additional complication, where parents can be perceived to block SDM. Parents can find it challenging to relinquish control over their child’s LTC for fear of poor health outcomes, and require clarification on their role from HCPs (26). HCPs commonly report parents’ emotional state as a barrier to SDM (27). While adolescents value their parents' support in the decision-making process, they often prefer parents to have a lesser role. Adolescents with LTCs would like the chance to see HCPs alone to discuss sensitive matters, but are rarely offered this opportunity (1, 28). Parents worry about not receiving important information about their child's health, which they value over patient confidentiality (28). Discourse needs to take place between the three parties around adolescent confidentiality, which has the potential to empower and improve adolescent autonomy, and can allow them the opportunity to be forthcoming about potentially risky behaviours (28, 29). HCP training on how to foster parents to support their child's autonomy and involvement could be instrumental.

In line with previous findings (17), nearly all the adolescent participants indicate a desire for the same or greater involvement in the decision-making process, particularly as they gain more experience with their condition. HCPs' behaviour can improve adolescent involvement in SDM by ensuring they speak to patients directly, providing sufficient information about options, inviting questions, and making it clear that they want them to be involved. Being invited to participate has been previously identified by adolescents as an important facilitator for SDM (27). HCP Friendliness and direct communication are seen to be essential in adolescent healthcare delivery (12). HCPs also need to be mindful of other communication factors (e.g. tone of voice) when communicating with adolescents (12), as adolescents can fear judgement from HCPs, which has been previously reported to induce stress and affect disclosure (30).

Adolescents need to feel ready to try SDM, and feel it aligns with their developing identity, and sense of normality. Receiving a diagnosis of a LTC can change one's self-perception, triggering a multitude of emotions such as shock, anxiety, anger, fear and despair (31, 32). Adolescents recognise that their involvement preferences change, and it is vital that they feel they have control over this, as failure to meet involvement preferences can be detrimental to their well-being (1). In line with the core elements of SDM and patient-centred care, clinical strategies that elicit adolescents' context and perspective, provide support, and offer tailored guidance have been previously identified by adolescents as enabling their behaviour to change (33). Adolescents can vacillate between acceptance and avoidance of their condition, which affects the extent they engage during consultations. Adolescents with LTCs feel set apart from their peers socially and physically, but strive to live a normal life (34, 35). Having contact and support from other peers with a LTC is important in making adolescents feel normal, and peers can be seen as a resource to learn about LTC experiences and involvement (34). When SDM is seen as normative behaviour, it can encourage adolescents to be involved. Furthermore, SDM can allow for the selection of options which are most congruent with adolescents' values, preferences and sense of normality (5).

The adolescent participants often relay contradictory perceptions around their roles and involvement. They grapple with feeling that it is their right, and that they should be involved in decisions that affect them, but that doctors are the experts and they are worried about making the "wrong" decision. This battle can make it difficult for adolescents to identify their role during consultations. The concern of adolescents with LTCs around making a "wrong" healthcare decision has been reported before (36, 37). HCPs could cultivate adolescents' understanding of the SDM processes, which emphasise the importance of patient expertise, and help adolescents to view SDM as a balance which is in line with their own values and beliefs.

## 4.1 Limitations

Although we attempted to recruit an equal number of male and female participants, significantly larger number of responders were female. This responder gender bias has been reported in other qualitative studies with adolescents with LTCs (38, 39). However, themes identified from the interviews were not found to be distinct between male and female participants. With a low response rate this study may have limited generalisability, and those who are more willing to be involved in qualitative health research may also take a more proactive approach to involvement in healthcare decisions. However, there was a range of responsiveness during the interviews, which is reflected in the duration of interview recordings. Despite these limitations, there are considerable strengths to the study. The use of participatory methods proved effective in eliciting and representing young people’s perspectives and biographical narratives. The life grids afforded the respondents a degree of control over disclosure of sensitive issues. In previous studies this has been found to alter traditional interview dynamics in attempt to address the potential issue of perceived power imbalance between the researcher and participant (16, 40). This may be particularly important for adolescents, where perceived power and control are strong influencers of involvement.

## 4.2 Conclusions

Developing an understanding of barriers and facilitators to SDM as perceived by adolescents with LTCs is essential in order to improve long-term healthcare delivery, and encourage and support SDM involvement. The data presented could be used to inform the development of interventions aimed at HCPs, parents and adolescents with LTCs. Finally, although strategies can be developed to encourage and support adolescents’ involvement in SDM, it is crucial that even the decisions around the extent of involvement are also shared.

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# Appendix

## Table 1. Recruitment Summary

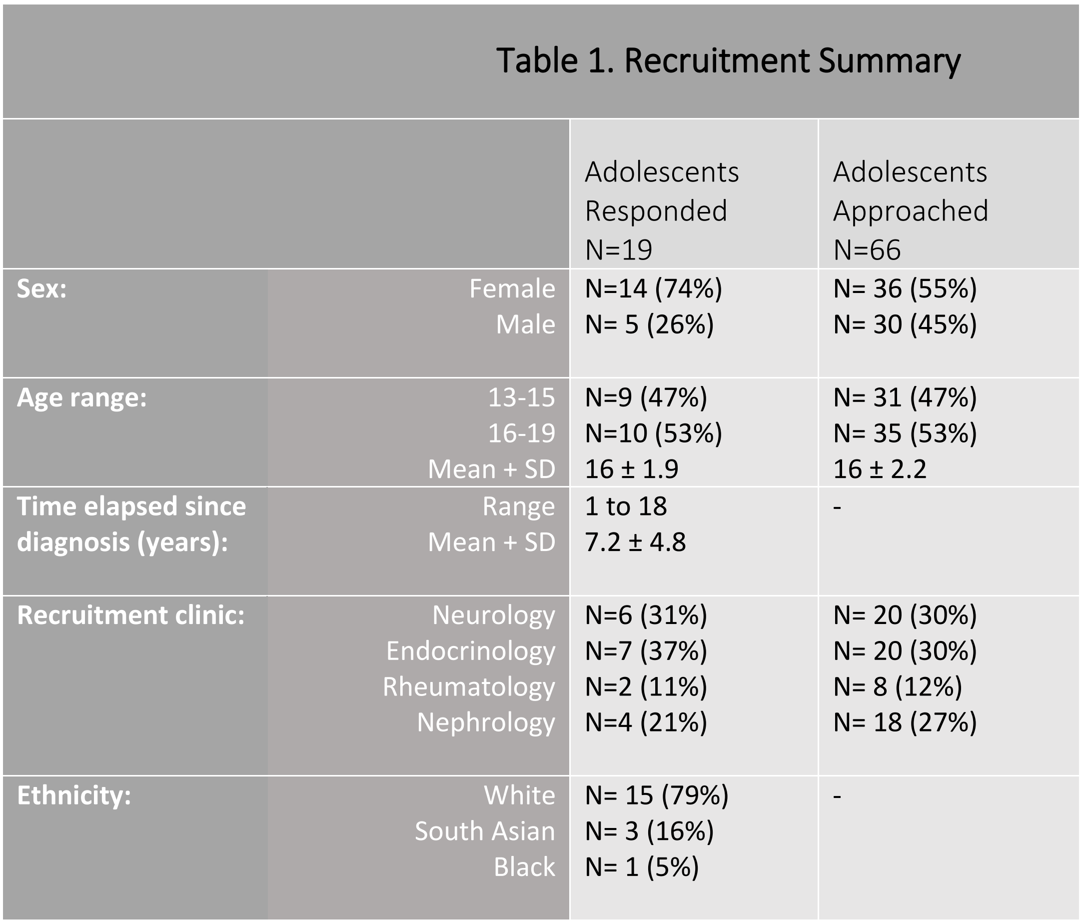


Table 1. Recruitment Summary

| | | Adolescents Responded N=19 | Adolescents Approached N=66 |
|---|---|---|---|
| **Sex:** | Female | N=14 (74%) | N= 36 (55%) |
| | Male | N= 5 (26%) | N= 30 (45%) |
| **Age range:** | 13-15 | N=9 (47%) | N= 31 (47%) |
| | 16-19 | N=10 (53%) | N= 35 (53%) |
| | Mean + SD | 16 ± 1.9 | 16 ± 2.2 |
| **Time elapsed since diagnosis (years):** | Range | 1 to 18 | - |
| | Mean + SD | 7.2 ± 4.8 | |
| **Recruitment clinic:** | Neurology | N=6 (31%) | N= 20 (30%) |
| | Endocrinology | N=7 (37%) | N= 20 (30%) |
| | Rheumatology | N=2 (11%) | N= 8 (12%) |
| | Nephrology | N=4 (21%) | N= 18 (27%) |
| **Ethnicity:** | White | N= 15 (79%) | - |
| | South Asian | N= 3 (16%) | |
| | Black | N= 1 (5%) | |

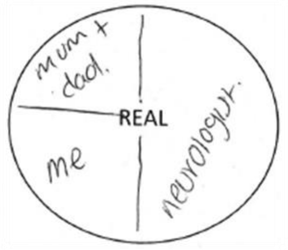
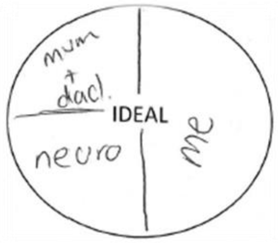
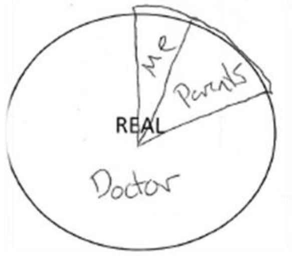
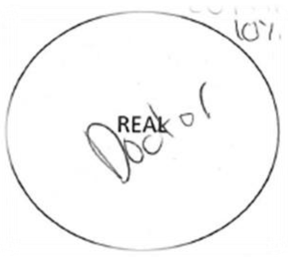
| Adolescents' perception of roles in a healthcare decision | Adolescents' desired roles in a healthcare decision | Adolescents' explanation of "real" versus "ideal" roles |
|---|---|---|
| <br> | <br> | "I guess cuz like the neurologist said I should, my parents said to give it another go and my epilepsy was so bad I had to give it a try again, even if I didn't want to I had to try." (Female, aged 18, neurology, 15 years) |
| <br> | <br> | "Maybe equal, maybe not my parents so much. I'm old enough now, like yeah, they don't need a say, they did before but that should change. I should have a say, and understand why and what I'm taking, you know?" (Male, aged 13, endocrinology, 13 years) |
| <br> | <br> | "Not everything the doctor says is clear like for us to understand so you know, having a say or asking questions may, like, make us understand more. So I can know what I have to do or if I was confused about something that, we should have our own say." (Male, aged 19, nephrology, 10 years) |
| <br> | <br> | "Because obviously I was just diagnosed, and they were like: "if you want to try it, you can try it, and then if you don't like it, you don't have to go on with it". I tried it for about maybe two weeks." (Female, aged 15, endocrinology, 5 years) |
| <br> | <br> | "I would have made the decision myself anyway cuz I knew at the time I wanted to go off it, that's what I had in my head. Um I guess I could have let them have a little say in it but it's just what I wanted to do so I, I would have allowed them like a quarter, not even that, because I at the time, I was determined I didn't want to be on any medication, so yeah" (Female, nephrology, aged 18, 18 years) |

Figure 1. Pie charts allocating perceived and desired role representation of adolescents, parents and HCPs in decision-making for specified healthcare decisions

## Table 2. Decisions described using pie charts

| Table 2. Decisions described using pie charts | |
|---|---|
| **Number of decisions** | |
| Total | N=39 |
| Range per participant | 1 - 3 |
| Mean + SD | 2.1 ± 0.7 |
| Mode | 2 |
| **Types of decisions** | |
| Begin treatment (e.g. insulin, anticonvulsants, analgesics) | N=15 |
| Change type/dosage/frequency of medication | N=11 |
| Change method of medication administration (e.g. from insulin injections to pump) | N=4 |
| Lifestyle changes (e.g diet, exercise) | N=4 |
| Discontinue medication | N=3 |
| Undergo Surgery | N=1 |
| Participate in a clinical trial | N=1 |
| **Adolescent role allocation: Desired vs actual involvement** | |
| Ideal = Real | N= 23 (59%) |
| Ideal > Real | N= 14 (36%) |
| Ideal < Real | N= 2 (5%) |

## Table 3. Sample Semi-Structured Interview Questions

| **Table 3. Sample Semi-Structured Interview Questions** | | |
|---|---|---|
| **Sample Interview Questions** | | **Sample Follow up Questions** |
| 1. | How have treatment options been presented to you in the past? | *How do you think treatment options should be presented?* |
| 2. | What do you think your/your parent's/HCPs roles should be in decisions and discussions? | *How does this compare to your actual roles?* |
| 3. | In what way do you think SDM is important? | *Why or why not?* |
| 4. | What has stopped you from being more involved in SDM in the past? | *How did you feel about that?* |
| 5. | What would make you want to participate in SDM in the future? | *How would this make you more involved?* |
| 6. | What are important things for you to consider when being involved in SDM? | *How do you express these considerations?* |
| 7. | How knowledgeable do you feel about your condition and how to manage it? | *(How) would you like this to change?* |
| 8. | How comfortable do you feel asking HCPs questions? | *What might make you feel more comfortable?* |
| 9. | What kind of information do you think HCPs need to know about you? | *(How) do you make sure HCPs know this information?* |

Table 4. Themes/ subthemes, their description, and exemplary quotes

| **Themes/ Subthemes** | **Description** | **Exemplary Quotes** |
|---|---|---|
| ***Interactional dynamics within the triadic relationship*** | | |
| **HCPs' communication approach** | HCPs either invite or prevent SDM involvement in the way they interact with adolescents and parents. | *"They* [HCPs] *will ask you questions sometimes, but we need to be encouraged to ask questions, not just sit there and listen. But they mostly talk to my parents, they talk to my parents more than they talk to me."* (Female, aged 14, rheumatology, 3 years) |
| | | *"They* [HCPs] *speak to me, so I speak back. I never used to ….. But now they've started speaking to me, I started speaking back" (Male, aged 14, rheumatology, 11 years).* |
| **Parental support of adolescent involvement** | Parents' support can facilitate involvement, however they often inhibit involvement by 'taking over' during consultations. | *"Probably just telling my mum to stop talking, it's difficult with her speaking all the time for me to speak as much as I think I should. I could probably ask her not to come in with me and she'd probably be ok with it. It would probably be much better cuz I could speak to him* [HCP] *and say like, yeah more stuff what I feel. They* [HCPs] *normally speak to both of us, but my mum normally is like: "Yeah, she's doing this, she's doing this, she's doing this" it's like mum, let me speak.* |
| | | *"I don't mind my mum helping if I forget something, but I liked it being able to speak myself in my appointment the other week. I prefer her to just be there to help, and me be the main person the doctor speaks to."* (Female aged 15, neurology, 5 years*).* |
| **Power Imbalance** | Adults are often seen as having more authority over the decision-making process. | *"I'm just happy to sit back and let them (adults) say what they want because obviously they know better."* (Male, aged 13, endocrinology, 13 years) |
| | | *"I really didn't have much of a say in it because I was under 18 so it wasn't my decision, it was basically down to the doctor and my mum."* (Male, aged 19, renal, 10 years) |
| ***Expression of autonomy*** | | |

| | | |
|---|---|---|
| **Sense of agency** | Adolescents feel they "should" be involved in decisions that affect them. | *"It's cuz obviously it does affect me at the end of the day, so I'd like to be involved as well as the doctor cuz, I dunno, it's my condition at the end of the day. I mean, I know it's diabetes, but everyone's diabetes is different, so I probably know my own a bit better than the doctor does. Just because you know yourself, and you know what's…you need to really, specially after you've had it for a while."* (Female, aged 15, endocrinology, 1 year) |
| | | "*Well, like it's important, it's your body, you need to have a say. Of course the doctors are the experts, but you know your body. They don't know how it feels to be you and live with it, and the effects."* (Male, aged 14, rheumatology, 11 years ) |
| **Sense of empowerment** | Adolescents need to feel they have control over the processes. Some adolescents disengage from discussions, and make decisions as a reaction to a perceived loss of control. | *"I understand they [doctors] have to say that, but there is times where it drags on to the point where I'm like: "Now you've said all this, I really don't want to do it, just because I'm so tired and bored of hearing it."* (Male, aged 13, endocrinology, 13 years) |
| | | *"I shoulda taken it, but it's, you're so in your own head about being like: 'Nah, no thank you' that you don't do it at that time, you just pull a strop. So, yeah, so I regret that a bit, abut as in like I felt in that moment I was a bit like: 'Well, I get a say in this' so I'm happy about that because I said 'no' I didn't follow through with whatever they told me, so it was like, can't listen to your doctor all the time, even though you should, there's moments where you just don't"* (Female, aged 16, neurology, 5 years) |
| ***Belief around own ability and value of contribution*** | | |
| **Perceptions around involvement outcomes** | How adolescents perceive possible outcomes of their involvement in SDM affects their attitudes towards being involved. | *"if they* [patients] *are involved they will know what's going on and then they can learn more"* (Male, aged 18, endocrinology, 5 years) |

|  |  |  |
|---|---|---|
|  |  | “*Sometimes I think people don’t do it because they’re scared of what the outcome’s gonna be if they put forward their decision*” (female, aged 14, rheumatology, 3 years) |
| **Perceived adequacy of own knowledge and skills** | Adolescents’ self-efficacy around involvement in discussions and decisions influences their actual involvement. | *“Cuz some of my things come out like daft, I come out with daft things. Or I'll be about half way through a blooming sentence and then like I've forgotten what I'm going to say, and we've got a finish with that conversation*.” (Female, neurology, 2 years) |
|  |  | *“Naivety. Just not knowing what, I wouldn't know what I was talking about, um the medications and stuff like that. I wouldn't know what to discuss. I don't know.”* (Male, aged 14 , rheumatology, 11 years) |
| ***Navigating personhood identity and patienthood identities*** |  |  |
| ***Endeavour for normality*** | Adolescents do not want to feel different, which can cause them to disengage during discussions. Contact with other young people in similar situations provides support and allows them to feel more “normal”. | “*Also, I think would happen if people, like you know the same ages, someone a year older or uh two years older or the same age as me has like a different illness, and say they have epilepsy and I have diabetes, we can speak about the similarities to it, and the differences to it, like how it affects you cos I think speaking with someone your age, sometimes friends are not enough, and sometimes talking with a stranger, not a stranger, but talking with someone with your type of thing helps*.” (female, aged 15, endocrinology, 7 years) |
|  |  | “*dunno maybe you do feel like it's a little bit unfair like, cuz obviously like you've gotta go to school with kids that don't have it and stuff, and then it's like just a bit unfair so like then you're in that mind-set and then you just, you didn't even, you can't be bothered asking things, stuff like that*.” (Female, aged 19, endocrinology, 6 years) |
| **Readiness to be involved** | Adolescents need to feel ready to be involved in SDM. This | “*I dunno, I just got too nervous when they were talking about* |

|  |  |  |
|---|---|---|
|  | usually develops over time from diagnosis. Lack of readiness can lead to avoidance and incite fearfulness. | *it, because like a lot of people don't like going into hospital, just nervous about just having to be there and didn't want to think about it*" (Female, aged 15, neurology, 13 years) |
|  |  | " *with this type of disease that can alter my life or whatever um and maybe just like a small amount of information at first so that, I don't know, people didn't get too panicked"* (Female, aged 19, renal, 4 years) |