Abstract

Objective: Young people and parents want to be more active in treatment decisions. Using the Theoretical Domains Framework (TDF) which segments behaviour change into barriers and facilitators across fourteen domains, the aim of this study is to explore the barriers and facilitators to shared decision making (SDM) from young people and their parents' perspectives.

Method: The sample comprised nine young people who presented with internalising difficulties and ten parents of young people with internalising difficulties across two sites in England. Interviews were conducted and transcripts were analysed using a deductive thematic analysis.

Results: Overall, 15 barriers to and facilitators for SDM in child and youth mental health were identified. Under capability, these included an awareness of SDM, forgetting discussions or not asking questions, clinician listening skills, and communication skills. For motivation, these included the availability of treatment options, availability of understandable resources, staff shortages, the environment being conducive to SDM, and if the school, or parents of young people, facilitated decisions. For motivation, these included whether SDM was thought to empower individuals, result in better treatment, or individuals making the 'wrong' decision, as well as whether individuals felt capable to be involved in treatment decision making, whether young people lacked capacity, and whether they could make decisions due to enhanced emotional states.

Conclusions: Barriers and facilitators across capability, opportunity, and motivation were identified. Interventions which target these barriers and facilitators may facilitate young people and their parents' involvement in decision making.

Keywords: Young Person; Parent; Mental Health; Shared Decision Making; Theoretical Domains Framework; Qualitative Research

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Introduction

There is increasing importance placed in Western healthcare settings on involving young people in decisions about their care and treatment (Makoul & Clayman, 2006). This has been advanced by increased clinician and researcher understanding of how young people understand and develop rights (Cheng et al., 2017; NHS England, 2011; Simmons, Hetrick, & Jorm, 2013; Westermann, Verheij, Winkens, Verhulst, & Van Oort, 2013). Policy documentation by bodies such as the United Nations has outlined children and young people have mandated rights to 'physical, mental, societal, spiritual, and moral development' (United Nations, 1959, 1989). Articles 12 and 13 in the United Nations Convention of the Rights of the Child specifically address treatment decision making. They state that children and young people should have their views taken seriously and that their views should be given consideration consistent with their age and maturity (United Nations, 1989).

A review of interventions to facilitate shared decision making (SDM) found that most interventions were not underpinned by theory (Hayes, 2018). This theory–practice gap aligns with the wider field of SDM in other settings, and it highlights that single theories are unlikely to be sufficient on their own as they neglect other important elements of decision making such as environment, cognition, and the decision making tools themselves (Elwyn, Stiel, Durand, & Boivin, 2011). Two approaches which incorporate multiple theories have been suggested to address this: The Ottawa Decision Support Framework (ODSF) (O'Connor, 2006) and the Theoretical Domains Framework (TDF) (Cane, O'Connor, & Michie, 2012). Developed from behaviour change theory, the TDF contains 14 different theoretical domains which

are posited to affect an individual's behaviour. These 14 domains can further be split into three overarching categories: capability, opportunity, and motivation. How these domains map onto the categories is outlined in Figure 1.

[INSERT FIGURE 1]

Given that the majority of interventions in child and youth mental health are not theory-led (Hayes, 2018) the TDF (Cane et al., 2012) can provide a means for clinicians and services to incorporate aspects found from study findings to better include young people and families in decision making. The TDF may have advantages over the ODSF (O'Connor, 2006) as it is validated (Cane et al., 2012) and widely used to design behaviour change interventions. Whilst not explicitly developed for SDM behaviour, the TDF has been used to explore barriers and facilitators from the perspectives of clinicians involving young people with internalising difficulties and their parents in SDM (Hayes, Edbrooke-Childs, Town, Wolpert, & Midgley, 2018). Overall, 10 of the 14 domains were found to influence clinicians' ability to engage in SDM. Clinicians' knowledge, skills, decision-making processes, and behavioural regulation affected their capability to engage in SDM with young people and parents, whilst social influences and their environment affected their opportunity. Lastly, their beliefs about the consequences of engaging in SDM, beliefs about their capabilities, emotions, and professional role/identity affected their motivation (Hayes et al., 2018). The TDF has yet to be used with young people and parents to explore their capability, opportunity, and motivation to engage in SDM.

There are a lack of studies exploring barriers and facilitators to SDM in relation to including young people in care and treatment. Instead, studies have focused on broader concepts such as person-centred care (Gondek et al., 2016). Barriers and facilitators to SDM from the perspectives of young people have been identified in five papers (Iachini, Hock, Thomas, & Clone, 2015; Offord, Turner, & Cooper, 2006; Oruche, Downs, Holloway, Draucker, & Aalsma, 2014; Pycroft, Wallis, Bigg, & Webster, 2013; Simmons, Hetrick, & Jorm, 2011). Prominent barriers and facilitators for young people included: information sharing between clinicians and young people (Iachini et al., 2015; Simmons et al., 2011), whether clinicians listened to, respected and validated young people (Offord et al., 2006; Pycroft et al., 2013), communication between young people and clinicians (Pycroft et al., 2013; Simmons et al., 2011), and the role of parents in involvement (Iachini et al., 2015; Oruche et al., 2014). Others focused on available resources to facilitate SDM (Oruche et al., 2014).

From the perspectives of parents, there are even fewer studies, with three exploring barriers and facilitators to SDM (Iachini et al., 2015; Oruche et al., 2014; Simmons et al., 2011). These included information sharing between clinicians, young people, and parents (Iachini et al., 2015; Simmons et al., 2011); confidentiality procedures and whether young people had the capacity for involvement (Simmons et al., 2011); providing culturally competent care and whether clinicians had knowledge of other services (Iachini et al., 2015); and what resources were available (Oruche et al., 2014). Whilst these studies help us to begin to understand barriers and facilitators from the perspectives of young people and parents, many have been conducted outside the UK (Iachini et al., 2015; Oruche et al., 2014; Simmons et al., 2011).

Research to date has outlined that most SDM interventions focus on externalising difficulties (Cheng et al., 2017). Despite this, recent research suggests that the prevalence of internalising difficulties is increasing in young people (Deighton et al., 2018; Fink et al., 2015), and that increased severity of difficulty, rather than whether difficulties are classified as internalising or externalising, predicts lower levels of SDM (Butler, Weller, & Titus, 2015). When interventions do exist for internalising difficulties, they appear to be targeted at 'older' teenagers (Simmons, Elmes, Mckenzie, Trevena, & Hetrick, 2016; Simmons et al., 2013) who may be attending the appointment without parents and are 'competent to consent' to treatment decisions.

There is a lack of studies exploring barriers and facilitators to SDM in child and youth mental health, particularly with regard to younger adolescents and those with internalising difficulties. The TDF has been used to explore barriers and facilitators to SDM from the perspectives of young people and may help address the theory–practice gap when it comes to intervention development. Based on the above, this study aims to examine the barriers and facilitators to SDM from the perspectives of young people with internalising difficulties along with parents in outpatient clinical settings in England.

Methods

Participants

Two services based in England took part in this research. Both were part of the National Health Service (NHS), a public healthcare system. One service (Site A) was

based in a town in the east of England. This site featured a multidisciplinary team offering assessment and follow-up appointments to children, young people, and families aged 0-25. The second service (Site B) was based in a city in the Midlands. Site B also offered assessment and follow up appointments to children, young people, and families aged 0-25. Both provided targeted and specialist services for young people. However, Site B was larger than Site A and offered a more diverse range of services.

To be eligible to take part, young people had to be between 12-18, be currently attending CAMHS due to an internalising difficulty, have adequate English language skills, and assent to take part. A lower age range of twelve was chosen as research to date has mainly focused on older teenagers. Twelve was also deemed appropriate as it is the age in the UK that young people enter secondary school and gain independence to be able to make decisions on their own or in conjunction with a family member. Parents or guardians in this study had to be responsible for a young person with an internalising difficulty who was attending CAMHS, have adequate English language skills, and consent to take part.

Overall, ten parents and nine young people participated. From Site A, four parents and three young people were recruited, whilst six parents and five young people were recruited from Site B. Of the parents and young people in the study, nine parents and young people were dyads, whilst an additional parent participated without their young person. Clinicians were responsible for recruiting eight young people and their parents, and the remaining two parents and one young person were recruited via the posters in the waiting room.

The parents interviewed were aged between 37 and 53 years old *(M = 44.7, SD = 5.85).* All were female. Nine identified as 'White British' and one declined to answer a question regarding their ethnicity. The ages of the young people at the time of the interview ranged between 12 and 17 years *(M = 14.5, SD = 1.43).* The nine young people interviewed were all the biological offspring of the parents interviewed. Three were male and six were female. Eight described themselves as 'White British' and one as 'Mixed Race'. The primary presenting difficulties for the young people were depression (*n* = 2), anxiety (*n* = 4), self-harm (*n* = 2), and an internalising difficulty not specified (*n* = 2).

Procedure

COREQ reporting guidelines (Tong, Sainsbury, & Craig, 2007) were followed (see appendix). The structure for the interview schedules followed the 14 domains of the TDF (Cane et al., 2012) and focused on the barriers and facilitators to SDM. The interview schedules were field tested with a parent and young person participation officer at the first author's institution, as well as a behaviour change expert at University College London, and no changes were made because of this. The interview schedule that was used can be found in the appendix.

Convenience sampling was used for this research. Clinical teams were requested to ask young people and parents on their caseloads if they were interested in taking part in the project. This form of sampling was used so that the researcher did not approach individuals who did not meet inclusion criteria (e.g. those whose primary presenting difficulty was not an internalising difficulty). Posters were also put up in

waiting rooms so that parents and young people could contact the researcher directly if they were interested in taking part. Those that expressed an initial interest were provided with an information sheet by the primary researcher via email. A time was arranged to follow up on any questions they had.

Three young people and three parents declined to take part after expressing interest. Four stated time reasons (e.g. exams and childcare arrangements), whilst two did not provide a reason. Following this, participants who still wanted to take part were asked to sign a consent form. For young people under the age of 16, an assent form was signed along with a parental consent form. Consent was taken separately for young people and parents and the young people were asked if they preferred being interviewed alone or with their parents to make them feel more comfortable. All requested being interviewed with their parents. All interviews were conducted at the participants' homes. Young people were asked questions first to minimise bias resulting from their parents' answers. The one remaining parent interview took place over the telephone.

Prior to the beginning of the interview, participants were re-briefed on the study and reminded that the discussion would be audio-recorded. All interviews were undertaken by the first author, a male PhD student (A1). At the time of the study, the first author had substantial experience carrying out interviews and focus groups on several projects. Prompts, outlined on the interview schedule, were available should a young person or parent feel stuck. After collecting demographic information, the first author asked for the interviewees' definition of SDM. For those that did not know what STM was or whose definition was incongruent with literature definitions, the

primary author clarified SDM as 'being involved in care and treatment decisions'. No repeat interviews were carried out. After the interview reflections and field notes were recorded by the researcher, these were subsequently discussed with supervisors. All interviews were transcribed verbatim.

Data analysis

The transcribed interviews were analysed using thematic analysis (Braun & Clarke, 2006) in NVivo (QSR International, 2015). Braun and Clark (2006) outline six steps that are undertaken as part of a thematic analysis. These consist of familiarising oneself with the data, the generation of codes, searching for themes, the reviewing of themes, defining and naming themes and producing a report. Application of the 14 Theoretical Domains to the data constituted a deductive thematic analysis, where each domain (e.g. 'beliefs about consequences') was applied to the data. Following this, subthemes within each imposed theoretical domain were inductively defined (e.g. 'SDM empowers young people'). A worked example of this is available in the appendix.

Once the primary researcher (A1) developed a coding key based on the transcripts and the TDF, the two research supervisors (A2 and A5) applied this to a subsection of transcripts ($n = 3$) to check the coding framework. One amendment was made to Professional Role. The new coding framework was applied by the primary author (A1), and no further changes were deemed necessary. Next, four transcripts (27%) were independently coded by a second researcher (A3) using the coding key. A

good level of agreement (Kappa = 0.81) was obtained using this method. The final

coding key, and an example of one developed code, are available in the appendix

Trustworthiness of findings

To establish the trustworthiness of the findings, nine recommendations by Shenton

(2004) were employed (see appendix).

Ethical considerations

Ethical consideration was sought and obtained from the London Hampstead NRES

Committee (REC ref: 15/LO/0997).

Results

Overall, eight domains of the TDF (Cane et al., 2012) were identified in this study as

either helping or hindering SDM. These spanned the areas of capability, opportunity,

and motivation and are highlighted in Table 1.

[INSERT TABLE 1 HERE]

Capability

The analysis of the young people's and parents' responses illuminated three

domains related to capability in regard to SDM. These were: knowledge, skills, and

memory/attention and decision-making processes.

Knowledge

Under knowledge, the following subtheme was identified from the young people and parents: different levels of awareness regarding involvement in decision making. This could be a barrier or facilitator to SDM depending on the level of awareness.

Different levels of awareness regarding involvement in decision making

There were differences between young people and parents' views regarding whether they knew they could be involved in SDM. Many young people stated that they did not know they could be involved in decision making.

> *'I didn't…[know]...they just make decisions for me'* (Young Person 7).

Conversely, most parents were aware they could be involved in care and treatment decisions from the beginning: *'I knew I could be involved' (*Parent 1). Whilst most parents knew they could be involved in decisions, they felt that clinicians did not make it clear to them what their role was in the decision making process.

Skills

The analysis revealed that all the parents and young people mentioned the person-centred skills needed by clinicians for successful SDM. This resulted in two subthemes: clinician listening skills inhibiting or facilitating SDM, and clinician communication skills inhibiting or facilitating SDM.

Clinician listening skills inhibiting or facilitating SDM

Most of the young people did not feel the clinicians listened to their point of view.

> *'[The clinicians]…wouldn't actually listen to what I had to say…I'd say, "No*
> *it's not, I know that because…" And that was kind of detrimental because*
> *they'd say that, and then everyone would believe what they'd said'* (Young
> Person 2).

Parents reported a more mixed response. Some reported feeling listened to; however, others felt left out of the decision-making process, either with their young person, or by the young person and clinician. In the latter scenario, this seemed to be more apparent as young people grew older and were seen by others as more capable.

> *'They don't talk to the parents, they don't … especially as the young*
> *person gets older, and it's as if you're non-existent'* (Parent 3).

Clinician communication skills inhibiting or facilitating SDM

A second important skill for SDM was effective communication by the clinician. Young people and parents highlighted that the way information was presented needed to be understandable if they were going to be involved in decision making

> *'Social and communication skills [are needed] ... the way that you talk to*
> *children … or parents who are usually absolutely stressed already'*
> (Parent 10).

Alongside the need for clarity of communication, interviewees described the excessive use of jargon or technical language by clinicians which they felt was a barrier to involvement.

> *'It's almost shoving the theory and science of it down your throat, isn't it …*
> *they've been trained all their lives in clinical theory and different ways to*
> *deal with people, but nobody's ever told them or taught them how to deal*
> *with people on a social level'* (Young Person 9).

Such instances resulted in young people feeling confused, bewildered, and not knowing how to proceed with treatment.

Memory, attention, and decision processes

The analysis of young person and parental responses under the domain memory, attention, and decision making indicated that the young people and parents sometimes forgot to ask questions or to remember all the information concerning the decision. This is explored below.

Forgetting to ask questions or to remember what was agreed

Whilst only mentioned by a few participants, it appeared that forgetting and remembering were sometimes associated with the individual's emotions (see Emotions below). For one parent, this was described in the context of the distress of looking after a child with a mental health difficulty, which made it difficult for the parent to make decisions in the first place.

'When you've got a child that's sick, your thinking processes aren't very

clear' (Parent 4).

For other parents, the large quantity of information covered in a session made it

difficult for them to remember things. Two parents spoke about taking notes during

the appointment to remember what was discussed and agreed (Parents 6 and 10),

whilst another parent spoke about everyone remembering 'bits of the conversation'

(Parent 5) so they could recall it later. Young people also highlighted that they often

forgot to ask questions which were important to them for decision making during the

appointment.

'I forget things because sometimes I get nervous and I forget to mention

things, even thoughts I'm feeling or anything like that. So that doesn't help

in decisions' (Young Person 8).

Opportunity

The analysis of young people's and parents' responses indicated that both domains

related to opportunity were involved in SDM. These were: environmental context and

resources, as well as social influences.

Environmental context and resources

In this domain, the young people and parents spoke of the following barriers and

facilitators: a lack of options regarding treatment, staff shortages affecting SDM, a

lack of comprehensible resources, and facilities not conducive to SDM.

A lack of options when it comes to treatment

A lack of psychological resources was cited by both the young people and parents. Rather than a choice between different options, the choice offered to one young person was that of treatment or no treatment at all.

> *'Options of treatments that I was presented with … it was just DBT'*
> (Young Person 5).

Alternatively, while there may be multiple options available, there could be very long waiting lists to access them. Several parents described having to wait over a year to access talking therapies for their young person (Parents 8 and 9), whilst one young person reported that they had been refused therapy as resources were '*spread so thinly'* (Parent 7).

Staff shortages inhibiting SDM

Staff shortages affected SDM in the form of parents feeling rushed and they they received insufficient explanation of the options that were available.

> *'I would say too big a workload for each individual member of staff… I just feel like everything is rushed'* (Parent 3).

The haste associated with appointments also resulted in decisions having to be made there and then, rather than allowing the young people and parents to think about their options in greater detail. In instances of feeling rushed, this sometimes

meant that the young people and parents questioned whether they had made the 'right' decision (Young Person 8).

Staff shortages also affected continuity of care. Some young people and parents highlighted that conversations and decisions made with one clinician were not known by others. A lack of continuity meant that when it came to sharing a decision, the young people had not built up a rapport within which they were comfortable expressing their views, values, and preferences.

> *'You know, it… quite often it was a different psychiatrist every time, wasn't it [young person]? You didn't feel that you were really comfortable speaking with them'* (Parent 7).

Facilities not conducive to SDM

Both the young people and parents highlighted that therapy rooms were often not adequately designed to facilitate SDM and that they made them feel uncomfortable. One young person likened the experience of being in a CAMHS appointment to being reprimanded in school, where they were placed into isolation if they had done something bad.

> *'You kind of feel like you're being told off in here. It's like being in isolation'* (Young Person 3).

The parent of this young person described the room layout as '*like you know you're in front of a panel'* (Parent 3). Others spoke of the building as *'oppressive'* (Parent 10) and described how the clinicians facing the computer rather than them created

'an uncomfortable atmosphere as soon as you got in' (Young Person 9). This made

parents and young people feel their views could not be openly expressed.

A lack of understandable resources

Many young people and parents also highlighted that they needed simple,

comprehensible informational resources to help them make sense of situations.

Often, resources were presented on paper leaflets which the young people and

parents found '*too text book-y'* (Parent 9). This resulted in the parents and young

people not knowing what option to choose and deciding in some cases to defer to

the doctor.

> *'You felt bombarded by it [information], or you feel like you just don't get*
>
> *what's going on…and then you don't have your opinion; you let other*
>
> *people make it for you'* (Parent 1).

One young person highlighted they were able to be involved when they were

provided with an age appropriate book presenting information *'in a way that I could*

understand … it didn't have long confusing words, it put it very simply. It gave you

pictures and diagrams…' (Young Person 3).

Social influences

Under the domain of social influence, analysis of the interviews with the young

people and parents led to the identification of parents as potential facilitators to SDM.

Parents' support of young people's interests in SDM

Most young people interviewed viewed their parents as important when it came to decision making. Some saw their parents as having *'more knowledge than they did'* (Young Person 7), which meant they were better placed to make the decision. However, parents were also described in a supporting role.

> *'I always like your support, Mum, [when making decisions] because it's a nice feeling that someone's behind you'* (Young Person 8).

Whilst parents were generally seen as supportive, a few young people also outlined how they appreciated some time alone with the clinicians.

> *'The other thing is, on the other hand, sometimes a child may not feel comfortable explaining things in front of the parent'* (Young Person 2).

Time alone meant that the young people were able to discuss more personal things, preferences, or reasons that may affect treatment and support, which they either did not want their parents to know about or did not feel comfortable discussing in front of them.

Motivation

Three domains around motivation were identified within the young people and parent interviews regarding SDM. These were: beliefs about consequences, beliefs about capabilities, and emotions

Beliefs about consequences

Three subthemes were identified in relation to this domain. These were: SDM empowers young people, SDM results in better treatment plans, and SDM can result in the wrong decision.

Shared decision making empowers young people

All young people stated that when they were involved in decision making, this made them feel empowered.

> *'It makes you feel more powerful and more trusting'* (Young Person 4).

For the parents, feeling like they were not involved in decisions gave them a sense of disempowerment. One parent described feeling like a bystander in their young person's care, which left them vulnerable and beholden to the clinician's judgement.

> *'… as a parent, that can make you feel quite powerless and out of the loop and quite vulnerable. Like you're making your child quite vulnerable because you're trusting them with other people …'* (Parent 4).

Shared decision making results in better treatment plans

A common theme identified across many of the interviews for both the parents and young people was that being involved in decisions would result in a treatment plan that was right for them. They viewed their difficulties as unique and felt that to gain effective treatment, these factors needed to be considered.

'You're treating the child as an individual and looking at their specific

needs. And you know, we're experts in ourselves' (Parent 8).

In addition, involving the young people in decisions also meant that *'treatment could be changed if needed'* (Young Person 5). Positive ripple effects stemming from this included more '*buy in'* from parents (Parent 9), as well as benefits to the young person's '*health and wellbeing'* (Young Person 8).

Shared decision making can result in the wrong decision

A few parents and young people discussed the negative impacts of making a 'wrong' decision.

'If you make the wrong decision, that could be worse for you … Because

you're only a child and sometimes you can struggle with what to do'

(Young Person 8).

Parents often described feeling a greater sense of responsibility than young people when it came to decision making. Medication was a subject that parents felt strongly about and did not view as a first line treatment for their young person. '*It's not all about medication and I think that's the biggest thing'* (Parent 9). Despite this, some parents questioned whether refusing a treatment (i.e. medication) was necessarily the right decision, as this could result in their child not benefitting from something that could help.

Beliefs about capabilities

Regarding beliefs about capabilities, two subthemes were identified: the parents' beliefs that they were capable of being involved in SDM, and the young people's capacity to be involved in SDM.

Feeling capable of being involved in SDM

During the interviews, parents expressed that they felt capable to be involved in care and treatment decisions.

> *'Yeah, I feel I have the capability to be involved'* (Parent 2).

Reasons for this included the parents having an intimate knowledge of the young person which was needed as part of the decision-making process, as well as the parent knowing what might work and how the young person might respond.

A lack of capacity inhibits SDM

The young people and parents both viewed a young person's capacity as a significant factor that affected their ability to be involved in decision making. For some, capacity was described in an idiosyncratic manner and was not linked solely with age or having a specific mental health difficulty.

> *'I think it depends on understanding because you could have somebody that doesn't understand at my age'* (Young Person 9).

Other young people discussed being *'too ill'* (Young Person 5) to be involved due to their mental health diagnosis. Some parents also reflected this belief.

> *'Obviously, you couldn't allow it to be entirely the patient's decision if you didn't think that their mental health was in the condition to make those sorts of decisions'* (Parent 7).

Despite acknowledging that capacity could affect SDM, the parents felt that young people *'should still be able to be involved in decisions'* (Parent 2). Involvement was described through the process of listening to the young person so that '*everything can be analysed afterwards as to how much of it you can actually accept and move forward with'* (Parent 6).

Emotion

Enhanced emotional states inhibit SDM

Barriers and facilitators to SDM around this theme involved enhanced emotional states. For the young people, these were sometimes linked to their mental health. Feeling sad or low were suggested as emotional states that could negatively impact SDM by causing young people to disengage from treatment.

> *'It's so much to do with their state of mind. Some of them may already be so depressed that they think what's the point? Nobody's listening, or I'm never going to get any better'* (Parent 6).

Others acknowledged that feeling strong emotions could make it harder to think about and share decisions, as things could become '*muddled … confused … not making sense*' (Young Person 3).

Discussion

The aim of this study was to investigate young people and parents' perspectives of the factors that affect SDM in child and youth mental health. Within this sample, eight areas of the TDF (Cane et al., 2012) were elaborated upon by participants.

Previous studies have highlighted the important role information plays in SDM. When information is given in a clear and understandable way, this can be a facilitator to SDM (Iachini et al., 2015; Simmons et al., 2011). Conversely, the same studies highlight that having no available information or receiving complex information can be a barrier to SDM. This study highlights that young people and parents want resources which are simple and understandable. Without such information, the young people and parents described struggling to be involved in decision making as they could not differentiate between options.

The role of communication between stakeholders has also been described in previous studies as a barrier to decision making (Simmons et al., 2011). Both the parents and young people in the present study viewed communication as an essential skill required by clinicians to engage in SDM. Specifically, clinician communication needed to be comprehensible to stakeholders for them to be meaningfully involved. Ways in which effective communication could be demonstrated by the clinician included the use of iterative questions, the removal of

jargon from speech, and the omission of complicated medical information. The importance of appropriate language has been highlighted in other studies, in which a young person's numeracy and literacy level has been shown to be an important factor when sharing information during treatment discussions (Schachter, Tharmalingam, & Kleinman, 2011).

Listening skills, which are closely associated with communication skills, were described as affecting SDM. Some young people and parents described how they felt clinicians did not listen to them, went through questions without paying attention to their responses, and made them feel inferior as a result. Listening skills have also been highlighted in previous studies as a facilitator to decision making when they are present, and a barrier when they are absent (Offord et al., 2006; Pycroft et al., 2013). Potential reasons for this lack of listening skills have been discussed in previous studies, whereby the clinicians described feeling overextended as they needed to complete a number of tasks prior to the appointment ending (Hayes et al., 2018).

Staff shortages were described as having an impact on the continuity of care, which affected decision making as the stakeholders felt they had to repeat the same information to new clinicians. For young people, this prevented the opportunity of developing a relationship or rapport with a clinician and hindered their willingness to communicate. The findings that young people do not want to speak to multiple clinicians and that the development of trusting relationships with clinicians allows young people to 'open up' have also been described in other studies (Oruche et al., 2014; Pycroft et al., 2013; Simmons et al., 2011). This is particularly relevant in child and youth mental health in the UK, as individuals may be seen by one professional

for assessment and then be referred on to someone else for a specific treatment modality.

The role of parents in young people's decision making was described as important by both parents and young people, and it was acknowledged that parents may possess greater knowledge than their child and could support their child in making decisions. Previous studies have highlighted the role of parents as facilitators in decision making for similar reasons (Iachini et al., 2015; Oruche et al., 2014). However, one study produced mixed findings which outlined both the positive and negative consequences of parental involvement in their young person's decision making (Simmons et al., 2011). On the one hand, parental involvement could mean that the young person feels supported. However, parental involvement could also be detrimental, as the parent might unduly influence decisions. Within the present study, young people stated that their parents were supportive of them being involved in decision making. Whilst no negative aspects of caregiver involvement were reported, the young people stated that they appreciated time on their own with a clinician to discuss things that they did not want their parents to hear. This may hint at the potentially negative effects of parental involvement, as the amount of privacy afforded to the young person could influence the conversation and the decision that is ultimately made.

Both young people and parents described the positives of being involved in decision making, which included the young person feeling empowered and receiving a tailored treatment plan that was right for them. Simmons et al. (2011) identified similar themes, finding that decision making was associated with adherence, the

engagement process, and empowerment. Another study described how involvement

in decisions could motivate young people to participate in treatment (Oruche et al.,

2014). One explanation for this could be that SDM helps create 'buy in' through the

process of co-creation around treatment and values. This replicates findings

exploring barriers and facilitators to SDM using the TDF with clinicians (Hayes et al.,

2018). Whether young people have the capacity to be involved in decision making

has been previously discussed (Coppock, 2005; Ruhe, Wangmo, Badarau, Elger, &

Niggli, 2015). Results from this study indicated that both the young people and

parents identified situations in which capacity might hinder a young person's ability to

participate fully in decision making. This was discussed both in terms of age and

mental health diagnoses, and particularly regarding Gillick competence for older

adolescents. Parents interviewed in the present study believed that young people

should always be involved in the decision-making process through having their views

acknowledged and validated, even if they may not be the main decider. This aligns

with previous research that states that there are differences between involvement in

decision making and being the ultimate decision maker (Alderson & Montgomery,

1996; Simmons et al., 2011).

Potentially choosing the 'wrong' option was highlighted as a negative consequence

of SDM, as it had the potential to impede recovery or make symptoms worse. This

theme has been highlighted previously when exploring barriers and facilitators of

SDM using the TDF (Hayes et al., 2018). In the previous study, a clinician spoke of

choosing the wrong option in relation to anxiety disorders and exposure experiments,

which they felt patients would not do for short-term relief. In this study, young people

and parents spoke more generally about making a wrong decision. To counteract such concerns, the clinician could present evidence regarding the possibility of becoming better with each option. This would need to be in a comprehensible format and take into consideration numeracy and literacy skills, thus ensuring that all stakeholder have all the necessary information to make decisions they perceive to be better for them which are also in line with their values and preferences.

A strength of this study is the use of the TDF (Cane et al., 2012) to examine the barriers and facilitators to SDM. Rather than asking individuals what they thought the barriers and facilitators of SDM were, a more systematic approach was employed that examined fourteen domains and was underpinned by theory. Whilst young people and parents were interviewed together, it may be useful in future research for the clinician to have been interviewed as well about the same decision-making experience. This would allow for a comparison of the barriers and facilitators from all perspectives related to the same treatment session, rather than the broader, more diverse experience identified here.

A limitation to this research is the way in which the young people and parents were recruited to participate in this study. Whilst clinicians were asked to outline the research to all eligible participants within their caseloads, most young people and parents came from a few clinicians who were actively involved in the study. To overcome this, posters about participation in the study were also put up in the waiting rooms. Whilst the posters recruited two parents and one young person to the study, most of the participants were referred by clinicians. The clinicians acting as

gatekeepers could mean that the participants recruited in this study may not represent an accurate sample of the target population.

A further limitation is the number of participants that were interviewed as part of this study. Whilst ten parents and nine young people allows for themes to be identified, this sample size may be insufficient to allow for a saturation of themes. As a result, some domains (e.g. optimism) which were not found in this study may have been identified if more young people and parents were interviewed.

The fact that the young people and parents were interviewed together could also be considered both a strength and a limitation. In terms of a limitation, it could be that individuals withheld information from the interview due to the presence of the other, which resulted in less rich and candid answers than if they had been alone. On the other hand, being in the presence of someone familiar who they trusted may have allowed them to be more open.

Conclusion

The TDF may be a useful way of deducing the theoretical aspects of behaviour change that are relevant when designing SDM interventions for young people and parents. To create a partnership between stakeholders, services should go beyond increasing knowledge through education and address aspects related to young people and parents' opportunity and motivation around SDM.

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