Making choices about medical interventions: the experience of disabled young people with degenerative conditions

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Abstract

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Background Current western policy, including the UK, advocates choice for service users and their families, taking greater control and being more involved in decision making. However, children's role in health decision making, especially from their own perspective, has received less research attention compared to doctors and parents' perspectives.

Objective To explore the perspective and experiences of disabled young people with degenerative conditions as they face significant medical interventions and engage in decision-making processes.

Design and methods Findings from a longitudinal qualitative study of 10 young people (13–22 years) with degenerative conditions are reported. Individual semi-structured interviews were conducted with participants over 3 years (2007–2010); the paper reports data from all three interview rounds. Interviews focused on medical intervention choices the young people identified as significant.

Results Although the young people in this study felt involved in the medical intervention choices discussed, findings demonstrate a complex and diverse picture of decision making. Results highlighted different decisional roles adopted by the young people, the importance of information heuristics and working with other people whilst engaging in complex processes weighing up different decisional factors.

Discussion Young people's experiences demonstrate the importance of moving beyond viewing health choices as technical or rational decisions. How each young person framed their decision was important. Recognizing this diversity and the importance of emerging themes, such as living a normal life, independence, fear of decisions viewed as 'irreversible' and the role of parents and peers in decision making highlights that, there are clear practice implications including, active practitioner listening, sensitivity and continued holistic family working.

Background and literature review

This paper explores the decision-making process and experiences of disabled young people with degenerative conditions facing choices about significant medical interventions. This is an important area because, as documented later, although current western policy advocates choice for service users and their involvement in decision making, past research has focused largely on doctors and parents' perspectives. This paper begins to address this knowledge gap. It concerns disabled young people with degenerative conditions, a specific group with complex and disparate health-care needs. Health considerations and decisions are an on-going reality for this group of young people, and hence, they are well placed to discuss health decision-making experiences.

Current policy: choice and participation

Within western societies, the involvement of children in making decisions about their health and health care has gained credence, frequently grounded in acknowledgement of the United Nations Convention on the Rights of the Child.¹ This recognition is reflected in research conducted in Europe²⁻⁴, America⁵⁻⁷ and Australia⁸, which has explored the role and practice of health professionals facilitating (or not) children's involvement in health-based decision making.

In the UK (the focus of this study), encouraging patients and their families to make choices and take greater control of their lives is a key policy and practice objective.^{9,10} It is also recognized that children, especially those with chronic conditions, should be involved in planning and making health-care choices regarding both their individual care¹¹ and service provision and planning.¹²⁻¹⁴

Health-care decision making in the family context

The importance of involving families in health-care decisions has been advocated for many years.¹⁵⁻¹⁷ However, past research has demon-

strated that theory and practice often diverge, parents do not always feel included and the voice of the child is frequently absent.¹⁸ A substantial literature on decision making in health care indicates that decision making is often a shared process involving health professionals, family members and other lay people.^{6,19,20} In families with older children, parents' role in decision-making processes is of particular interest. However, whilst there is some evidence regarding parents' and doctors' roles and experiences in this process²¹⁻²³ and their views on the role of the child,^{20,24,25} research on children's own perspectives is more limited. Existing evidence is often confined to particular conditions,^{20,26-28} such as cystic fibrosis²⁴ and oncology.²⁵

Children making health decisions

Amongst children, there is diversity in the degree to which they want to be involved in decisions about their health and treatment. From the limited research that has directly asked children themselves how much they want to be involved, age and gender do not always seem to be directly associated with children's preferences.²⁹⁻³¹ For example, Alderson and Montgomery's³¹ study of surgery decisions found that younger children did not necessarily want less involvement compared to teenage children, nor girls more than boys. Other factors, such as the child's previous decision-making experience, the type of decision and its perceived seriousness, appear to be important.

However, benefits of involvement in decision making have been highlighted, including retaining a sense of personal control and value, and feeling less anxious.^{4,29,32} Research with teenagers reveals the importance of treating them as individuals, understanding their perspectives and not forcing or hurrying decisions.³³ Barriers to involvement include poor relationships and communication between children and health professionals, children's marginalization in health-care consultations when parents are also present, and health professionals underestimating children's ability to participate in decision making.^{3,4,20,25,28-30,34-36}

Theoretical perspectives

Descriptive theories of decision making are useful because they are concerned with how individuals make 'real-life' choices, particularly when there is risk or uncertainty. Health decision making is a good example of such situations: outcomes may not be guaranteed or no single option is clearly 'the best'. Amongst the numerous descriptive theories of decision making, two theories were particularly helpful in developing the interview topic guides and supporting data analysis (especially, identifying initial coding themes). These were decision making in situations of uncertainty (prospect theory)³⁷ and its associated concept of framing³⁸ and the information process approach.³⁹

Prospect theory³⁷ was developed to describe decision making in situations where the outcome is uncertain. In this study, a particularly relevant aspect of this theory is the idea that decision making involves making trade-offs when personal gains and losses of each option are considered and evaluated against other options. Within prospect theory, there is also the concept of 'framing'.^{38,40} Framing is based on the argument that internal and external factors influence the way a decision is perceived. Thus, a single decision may be framed differently by two individuals depending on their individual beliefs, previous experiences, personality, knowledge and understanding of an issue and social context.^{37,39}

Information-processing approaches³⁹ describe ways in which strategies (both conscious and unconscious) are used to manage and simplify information processing and its cognitive demands. One mechanism is heuristics.³⁹ Heuristics (or mental shortcuts) are internal rules or strategies which individuals use to reduce the 'cognitive demands' of decision making. Heuristics may be used to control the amount of information gathered prior to making a decision (for example, only seeking information and advice from a limited number of individuals) or to reduce the number of options under consideration (for example, only considering options that fulfil certain criteria). Heuristics is also used to simplify the process of weighing up different

options (for example, using a fixed set of criteria to judge options and choosing the first to satisfy these criteria). The heuristics used in a particular situation will depend on individual characteristics as well as the nature of the choice and its perceived impact on the individual. The use of heuristics was felt to be an important area to explore in this study as the young people faced potentially complex medical information, advice from a range of sources (medical and lay) and had different personal circumstances. Heuristics provided a tool to begin to understand how young people made sense of and navigated significant medical choices.

Information-processing theories stress the way that decision making can be cognitively demanding. This may mean that children are less 'effective' decision-makers in complex decisional situations, especially if they lack experience.⁴¹ However, insights from the aforementioned theories were felt to be transferable to the young people in this study because of their older age and past experience of choice-making evolving from deteriorating health.

Method

The findings reported here are drawn from a larger, longitudinal qualitative study involving three groups of disabled and/or chronically ill people (adults, older people and young people) over 30 months. The main aim of the study was to explore how individuals make service-related choices (health, social care and education) when their needs change over time, particularly in the context of degeneration. Ethical approval was received from an NHS research ethics committee.

Twenty-seven young people with degenerative conditions and their families participated in the project. They were recruited from two English hospices. Hospice staff sent out project information to all families with a young person aged 13–22 years^a with a degenerative condition. Families contacted the researcher if they wished to participate. Recruitment proved challenging,

^a22 years may be regarded as a young adult. However, for brevity the term young person will be used.

and this is reflected in the small sample size. Reasons for participants' non-response were not collected, but hospice staff indicated that deteriorating health had affected recruitment. The sample varied in terms of age, gender, ethnicity and health condition. Sample characteristics are documented in Table 1.

At each interview, the young people were asked to choose a recent decision (within 2 years) that was important to them. This formed the focus of the interview. Discussion of health choices was not an interview requirement. Ten young people chose to talk about significant health interventions (such as spinal surgery and gastrostomies). This paper focuses on the 10 young people who discussed health choices. The remaining 17 young people discussed other choice areas (social care, education and leisure options).⁴²

The interviews

The data were collected during three semi-structured interviews conducted between 2007 and 2010. Young people's topic guides were modified versions of topic guides used across

the study. They were shorter and used simpler language. For the younger young people (13–16 years), the topic guide was quite structured, and the topic guide for the older young people (17 plus) used a more open, discursive format.

At each round, interviews explored decision-making processes associated with new, on-going and completed choices. Core topics, such as sources of information, factors considered and outcomes of decisions, were discussed. During second and third interviews, participants were asked to reflect back on decisions they had already made. For some decisions, it was possible to obtain a longitudinal perspective as participants discussed anticipating, making and then the outcomes of a choice across different interview rounds. For other decisions, participants chose to describe a choice they had already made. The benefits of repeat interviews were developing a relationship with participants over a number of meetings that yielded increasingly rich data and discussed longer-term outcomes. In addition, choice reflections could also be explored.

Table 1 Young people and their decisions

Identity code	Gender	Age ¹	Ethnicity	Condition	Intervention and decision	Intervention discussed at interview number
YP1	Male	17	British Pakistani	DMD	Gastrostomy – declined	1
YP2	Male	13	White British	Cystic fibrosis	New nebuliser – accepted	1, 3
YP3	Female	16	White British	SMA	Spinal rods – accepted	1
YP4	Male	19	White British	SMA	Gastrostomy – accepted	1
					Epilepsy medication – rejected, then accepted	1
YP5	Male	17	White British	Complex health needs	Adapting nasal feed – accepted	1
YP6	Male	14	White British	DMD	Spinal rods – accepted	1
					Gastrostomy – decline planned	1
YP7	Male	14	British Pakistani	DMD	Spinal rods – declined	1
YP8	Female	21	White British	Complex health needs	Gastrostomy – accepted	1, 2, 3
					Kidney dialysis – declined	2, 3
					Resuscitation and assisted ventilation – declined	1, 2, 3
YP9	Male	14	British Pakistani	DMD	Spinal rods – declined	1, 2, 3
					Gastrostomy – accepted	2, 3
YP10	Male	22	White British	DMD	Gastrostomy – declined	1, 2, 3

DMD, Duchenne muscular dystrophy; SMA, Spinal muscular atrophy.

¹Age at 1st interview.

Table 1 documents the nature of the health decision(s) discussed by participants and the interview round(s) during which this decision was discussed.

Written consent was gained at each interview. For young people 16 years or under, parental consent was also obtained. The interviews (60–90 min) were conducted in young people's homes. All were audio recorded with the young people's consent. As the study discussed or could raise potentially sensitive or distressing issues for participants, the project organized a support person in each hospice to provide information and/or counselling if required by the young people. The young people were informed of this person.

Data analysis

Interviews with young people were fully transcribed and analysed using the Framework Approach.⁴³ This involved four stages: first, data 'immersion' (reading transcripts) and the development of a coding frame from *a priori* themes and topics alongside emerging themes. The former included key concepts from the previously noted descriptive theories of decision making. For example, when coding the transcripts, a memo was made to note any information-processing heuristics being used by the young people, and when coding choice options, a memo was similarly made to highlight positive and negative aspects the young people discussed and evaluated, that is, trade-offs. Second, the verbatim text was coded (this study used MAXqda software for this). Third, coded data were summarized and displayed in a set of thematic charts. Finally, the charts were scrutinized to identify themes and patterns in the data and draw comparisons. Data from the three interview rounds were entered on the same charts alongside the source of data (i.e. interview round number). Organizing the data in this way allowed the biographical flow⁴⁴ of participants' accounts to remain intact as they reflected and/or revisited choices at different points in time.

To aid methodological rigour, the researcher worked alongside project colleagues continually

discussing analysis. For example, during the development of the coding frame, four young people's transcripts were double-coded by the research team to check consistency and interpretation of the coding frame. The researcher also discussed how the data should be charted and the development of charts with colleagues.

Results

Findings reported here concern the decision-making processes described by disabled young people with degenerative conditions (13–22 years) facing a choice regarding a medical intervention which they perceived as 'significant'. Within the sample, different choices were made: some chose to accept an intervention, others rejected or postponed what was being offered. The findings are reported in such a way to reflect the chronological process of decision making: from examining the decision, investigating options, making a choice, to reflecting on the choice made. Reporting the results as a chronological process also highlights how the aforementioned descriptive theories were used by the researcher to understand how, at different stages of the decision-making process, the young people made sense of their actions and the choice(s) they faced. For example, when exploring the decision, framing was important; when investigating options, information heuristics came to the fore, and when making the choice, the young people drew on a complex interplay of framing, the use of trade-offs and heuristics.

The decision

Why was the decision raised?

The medical interventions the young people chose to discuss arose from their deteriorating health. However, not all were first-time decisions. For half, the decision had been previously considered and rejected or postponed, leading it to become an 'on-going' choice to be revisited when (medical/health) circumstances demanded or the young person initiated revisiting the decision. Sometimes, participants believed they

controlled when a decision was reconsidered, feeling they still had a choice. At other times, they felt the timing of when a choice was reconsidered lay with other people or with changes in health circumstances beyond their control (for example, the medical necessity of an emergency gastrostomy).

Decisional roles

The young people reported that decisions about health interventions were typically initiated by medical professionals, usually consultants. Only two participants had initiated discussions about a medical intervention with their doctor. In both cases, past or on-going experience was the reason for this. For example, one participant experienced a painful and relatively unsuccessful spinal rod operation that, retrospectively, he felt had been conducted too late. This taught him the importance of early, pro-active discussion and planning.

Although doctors usually initially raised the decisional problem (i.e. whether or not to accept a medical intervention), this did not mean the young people played a passive role in subsequent decision-making processes. A range of roles were described from young people taking responsibility; to sharing decision making with others (especially parents); to finally allowing another person (such as parents or doctors) to take a more leading role. Diversity was because of a number of factors including the perceived importance of a decision; whether it was as noted above, an 'on-going' decision; and whether the young people felt that they were the only one able to make the decision because they would be living with the health consequences of that decision. Revisiting a decision (for example, whether or not to accept a gastrostomy) appeared to encourage young people to assume a more active role. This may be because they felt familiar or more knowledgeable in these situations.

Young people's age was not directly associated with their role in the decision-making process. The extent to which younger participants played an active role in decision making varied. Similarly, whilst none of the older young people

felt another person had made the decision for them, sharing decision-making processes with others was important for many.

How decisions were perceived?

The way the young people framed the decisions showed that they perceived them as more than health decisions. Sometimes they were viewed as being more about supporting or inhibiting independence. For example, gastrostomies were perceived by some as decisions about relinquishing independence in one area of life (i.e. independent eating). The way relinquishing this independence was framed influenced the decision taken.

Another key theme in young people's accounts of their decisions was their irreversible nature; they were felt to be final decisions. Interventions such as gastrostomies and spinal rods (accurately or not) were viewed by young people as largely irreversible, and this increased the significance or 'weight' of the decision.

I didn't really want to take a gastrostomy but that, cos that would be, that would be me for the rest of my life and I didn't really want to make that decision ... (YP1: Interview-1)

In contrast, if a decision was framed as reversible, it was felt to be an easier decision to make: there was the possibility of 'trying out' options and/or changing one's mind.

I felt a strong feeling like, yeah, you know, go take it [nebuliser], try it, if you're not happy you can always change it. (YP2: Interview-1)

The options – information and advice

Gathering information about options is an important component of the choice-making process. There was diversity amongst the young people in terms of the type of information, how it was gathered, from whom and how much was gained or wanted. Some (4/10) wanted as much information as possible and reported asking their doctor numerous questions. These young people prioritized being informed, for two this arose from past experience of feeling uninformed by professionals. In contrast, past

experience of having too much information from professionals had left others feeling confused as it accentuated uncertainty about which option to choose.

Different sources were used by young people to access the different types of information they felt they needed to make a decision. Verbal information from professionals, especially doctors, was the most common type of information received. Young people wanted basic medical facts about the intervention they faced and generally felt that their doctor gave them enough information. Trusting this information was important as it provided a degree of certainty for the young people and was a useful heuristic in what was or could be a confusing time. Only one participant expressed concern that doctors could be biased or give selective information.

Young people also used information from other health professionals, such as specialist nurses, dieticians and physiotherapists. These professionals often acted as important interpreters of medical information using practical examples and pictures. For example, a specialist nurse showed one young man the type of portacath his doctor was proposing to insert. Personalized and relevant information from health practitioners who knew a young person's life context and medical needs and/or preferences was valued. Parents sometimes played an interpretive role: explaining or simplifying technical information. This was particularly the case for younger members of the sample.

Most of the young people had not (or could not remember) receiving written information. However, those who had received leaflets reported finding them useful. Only two participants had used the internet to search for information about the interventions they faced. One young person had chosen not to use the internet as it produced too much information that could be confusing and potentially 'scary'.

Talking to other young people with similar conditions who had faced the same intervention was used by three participants to add to their knowledge and understanding. They believed that other young people's experiences were helpful. Others drew on their own observations

of how other young people they met/knew had experienced and/or coped with the intervention they faced. These sorts of information were valued as providing 'insider' information: 'telling it like it is' rather than standard 'text book information'. However, the young people were aware that their peers' personal and health circumstances could be different and so believed it was best to draw on both medical and experiential information.

Making the choice

Table 1 shows that different young people made different decisions about the same type of choice. The key factors influencing the decisions made were the perceived impact of the intervention on: quality of life, independence and maintaining health/sustaining life. These were sometimes traded off against each other with differences between young people in their priorities being reflected in the decision that was made. In addition, individual differences in how invasive interventions were perceived and what constituted an acceptable level of risk also influenced the decisions young people reached. Each of these factors will now be explored in greater depth.

The invasive nature of interventions

Over half the young people expressed a fear of invasive medical procedures and the pain associated with them. This was largely because of past experiences. Other aspects of invasive procedures were also voiced as a reason for not going ahead with an intervention. For example, gastrostomies leading to a hole in and/or tube protruding from the stomach were viewed as aesthetically unpleasant. In some cases, they were viewed as physically threatening. For example, two young people described a 'squeamish' reaction to this perceived invasion of their body.

Potential uncertainty and risks

The importance of uncertainty and risk pervaded most young people's accounts of decision making. For example, 8 of 10 highlighted outcome uncertainty surrounding the interventions

they faced. Fears centred on the degree of success surgery would bring. For example, how far would the insertion of spinal rods actually improve their posture, increase mobility and reduce discomfort? This was largely unknown by the young people.

They [doctors] were talking to me ... and then I thought whether to have the operation [spinal rods] and I just thought of the risks and stuff, so I just said like 'no, I won't have it' ... well, my back might be straighter but we're not sure, you know. (YP9: Interview-1)

Potential risks associated with undergoing medical procedures were also considered. General anaesthetics were viewed as extremely risky by those requiring assisted ventilation and were regarded as a valid reason for refusing an intervention.

Quality of life

Whilst the interventions under consideration may lead to overall health benefits, for some young people, there was concern that the intervention would adversely affect their quality of life. For example, three young people rejected a gastrostomy because they did not want to 'give up' or reduce the pleasure eating 'real' food brought. Another young person feared loss of social time with friends if she was 'hooked up' to a dialysis machine.

I probably would have to be in hospital like three or four times a week for like 6 h or something which would just like affect me social life I suppose and things I like doing. (YP8: Interview-3)

Maintaining current or future quality of life also contributed to the decisions young people made. Some young people spoke about the progressive nature of their conditions, and this heightened their desire to live 'as normal a life' as possible for as long as possible. The desire to preserve mobility was an important outcome during decisions, for example, although one participant feared spinal surgery, this was outweighed by her desire to go to university.

They said, 'you might need an operation and it might be a bit risky.' I was a bit like, 'ooh', you know but I think deep down I know that it was

necessary. If it weren't they said I'd become ill ... I know that my health would have deteriorated and I probably wouldn't go to university. (YP3: Interview-1)

Maintaining health

At other times, young people prioritized their physical health over quality of life. Gastrostomies were discussed as medical necessities to maintain health. Other potential benefits were also described, such as having more energy and being less susceptible to recurring chest infections.

Retaining independence

The perceived impact of an intervention on independence or autonomy was found to influence young people's decision-making processes. This was especially the case amongst older participants who had gained some measure of independence and were keen to maintain this.

I'm not bothered about anything else really as long as I'm independent. (YP4: Interview-2)

Interventions or procedures that increased or maintained independence were traded off against reduced independence, for example, for one young person retaining decisional control over her health care and preferences until the end of life was paramount. Thus, deciding to write a living will stating her wishes was viewed as a positive means to retain this control. Any intervention that was likely to increase dependence on others or technology was viewed negatively, and this negative outcome had to be weighed up against potential positive outcomes, such as extended life or better physical health.

Parents' wishes

All the young people were aware of their parents' views about the choice(s) they faced. Three specifically described how, in making their decision, they considered how their choice would impact on their parents' lives, for example, additional post-operative care which their parents would have to manage following spinal surgery.

The actual decision: who made it and when?

Across the sample, the decision to accept or decline the medical intervention was made at home rather than during appointments with a health professional. The actual decision was made either by the young person alone or arrived at jointly with their parent(s). Prior to this, talking to parents was important. Parents (especially mothers) provided emotional support and acted as sounding boards, listening to young people's fears and concerns. The young people reported finding it easy to talk to their parents. For some, this contrasted with feeling unable to share their concerns with their doctor. Trust was apparent: the young people trusted parents to listen to them, understand their feelings and respect their wishes.

Parents also played an important role reaffirming young people's decisions. Very little conflict with or different opinions to parents were mentioned. Only one young person reported a difference in opinion with his mother. This absence of conflict contradicts commonly held stereotypes of how young people make decisions⁴⁵. In this study, the reason for this consensus was generally explained as 'being of a like mind'. This arose from two factors: shared health experiences and shared priorities in terms of the young people's health and well-being. Within the former, a shared sense of understanding was felt to have evolved over time between the young people and their parents with regard to the young person's health, their deteriorating condition and associated changing health needs. This understanding was respected and valued by many of the young people. In addition, consensus was also facilitated by shared family values when it came to the young people's health such as, prioritizing a normal life over sustaining life at any cost.

The older young people (16 years plus) still wanted their parents to be involved in decision-making processes because they valued their opinions and respected their knowledge (especially of their health condition and needs). At the same time, these young people also reported that, over time, their parents had increasingly passed over decision making to them and encouraged them to take greater control.

Reflections on choices made

The young people were often reluctant to reflect back on health decisions they had made, particularly whether or not they had made the right choice. Some explicitly noted the futility of looking back at past decisions, especially decisions that were viewed as irreversible.

I'm not a person who looks back, I always look forward unless it's something I want to look back on, you know. (YP3: Interview-1)

Only one young person voiced regret about a decision made. She had gone ahead with an intervention (a gastrostomy) and subsequently disliked its invasive nature but was also pragmatic about her health.

No, if I could go back now I probably wouldn't have it done to be honest. Yeah, but then I wouldn't be here [alive]. It's just, it feels so invasive ... (YP 8: Interview-2)

To summarize, the study found that the young people felt involved in decision making about significant medical interventions. However, a complex picture of choice-making emerged with young people adopting different decisional roles and preferences. Choice-making involved using different information selectively, working with other people whilst also weighing up the costs and benefits of possible decision outcomes such as invasiveness, threats to life, maintaining health and quality of life.

Discussion

Previous health decision-making research about ill children has called for more research exploring the role played by children, especially from their own perspective.^{28,29,36} Furthermore, Moore and Kirk²⁹ argue that much of the existing work is too broad, focusing on children making health decisions of varying importance and covering disparate age ranges. This paper begins to address these gaps by exploring the experiences of disabled young people with degenerative conditions making decisions about significant medical interventions. It also extends analysis beyond clinical settings to describe decision-making processes in informal contexts.

The young people in this study felt involved in decision-making processes; this contrasts with much of the existing literature.^{20,28,46} However, it is important to note that this study focused on young people, and some research²⁵ has noted that older children are consulted more than younger children. The findings presented also demonstrate a diverse picture of decision-making experiences for disabled young people with degenerative conditions. Similar to Alderson and Montgomery's³¹ study of children's surgery decisions, participants in this study wanted to be involved in decisions about their health, but preferences about the extent to which they took sole responsibility for decisions differed between them and also, for some, between the different choices they were making.

The young people's descriptions of their experiences demonstrate the importance of viewing health choices as more than technical or rational decisions.⁴¹ This reiterates the value, as noted earlier, of grounding health decision making in a holistic biographical perspective⁴⁴, in particular exploring how decisions are framed by each person.³⁸ Decisions that may appear irrational or unwise to others, such as health professionals, can be very rational to the person facing the decision.

Past research suggests that young people do not generally consider risks and benefits in decision making as much as adults.⁴⁷ Although this study did not compare young people and adults, what was clear was that the young people interviewed had engaged in a complex process of 'trade-offs' considering both the costs and benefits of accepting a medical intervention. Health and broader social and emotional quality of life factors were considered. For many, making these 'big' decisions could be a 'scary' process, especially when medical interventions were viewed as irreversible. The decision-making experiences of the young people who participated in this study have shown that the range of issues young people with degenerative conditions may consider when making a decision about a significant medical intervention and the strategies used to reach a decision.

The importance of normality, especially having a life beyond one's illness, is a key concern for young people with chronic health conditions^{48,49} (especially Abbott and Carpenter's⁴⁹ research). In this study, weighing up the costs and benefits of accepting a medical intervention involved difficult decisions for some young people. For example, retaining and/or preserving elements of a non-medicalized life (especially doing similar things to peers) sometimes drove the decision about whether to accept a medical intervention or not. In some situations, medical interventions were rejected to retain independence from medical technology. In other cases, medical interventions were felt to improve health and facilitate increased social participation. This diversity reiterates the importance of how young people framed decisions and their personal prioritization of a 'normal life'.

Medical technology, such as a gastrostomy, may bring health benefits, but it can also increase dependence. For some young people, this raised the further question of 'when' to accept a medical intervention. The accounts of young people participating in this study revealed that having or sharing control of decision making was important. In addition, whilst wanting to prioritize quality of life and independence, participants were also pragmatic and recognized when an intervention was a medical necessity, in terms of prolonging life and maintaining health. Balancing control and pragmatism was a personal experience for each young person as their health condition fluctuated and life circumstances altered. The question of 'when' to accept an intervention also demonstrated how some choices became 'on-going'. Revisiting past decisions could provide an opportunity to postpone making a final decision, thus avoiding making the 'wrong' decision.

Practice implications

Professional attitudes and behaviours can either facilitate or hamper young people's participation in decision making,^{28,29,36} and findings from this study raise a number of practice implications.

Revisiting choices

Recognizing the dynamic character of choice-making, its potentially 'scary' nature and the progressive but often fluctuating health experience of degenerative conditions, it is important for practitioners to provide opportunities, as and when appropriate, for young people to revisit or reassess postponed or previously made decisions. This may help ease some of the anxiety participants expressed surrounding fears of irreversible decisions.

Personalized information

The importance of information in health decision making is well documented.³⁶ In this study, young people used a range of information sources. Parents and specialist practitioners were reported as playing an important heuristic role: simplifying, interpreting and/or personalizing medical information. Practitioners, especially those who know a young person's health needs and wider socio-economic circumstances, can make general 'text book' medical information more accessible, relevant and meaningful.

Meeting other young people

The young people in this study valued discussing decisions with other young people with similar conditions. This suggests that health services should explore ways to further facilitate contact between young people with similar conditions who have faced/are facing similar health decisions.

Parental involvement

Young people valued and wanted (albeit in varying degrees) the continued involvement of their parents in health decisions as they moved towards/entered adulthood. Holistic family working is central to paediatric health care.¹³ However, the role of parents in supporting health decision making after the transition to adult health services has yet to be fully recognized and assimilated into practice. It is acknowledged that the transition to adult health services can be a difficult time for practitioners with the need to balance young people's rights, respect for parents' needs and/or wishes whilst also meeting professional responsibilities for protection/

safeguarding.^{20,35,50} These tensions may be more pronounced for young people with degenerative conditions as family dynamics and relationships can be further complicated by young people's ongoing dependence on parents into adulthood for aspects of everyday care.⁴⁹ Practitioner sensitivity to family dynamics, each young person's wishes and changing health circumstances are important. Potential role reassessment and how to facilitate and support this for young people and their families (especially parents) should be an on-going consideration for practitioners.

Study limitations and future research

This was an in-depth study, focusing on a small sample discussing some specific interventions. As with any qualitative research in a new area, the purpose was to explore and describe the range of views and experiences, but the nature of the sample means care needs to be taken when drawing conclusions and considering implications. However, repeat interviews provided an opportunity to explore decision making as a dynamic process within which participants could provide subjective reflections. These in-depth qualitative insights provide important additions to our understanding of the multidimensionality of health decision making.

Acknowledging this complexity and the limitations of this particular sample, there are areas further research could usefully explore, for example, decision making involving other types of 'high-risk' medical decisions (for example, urgent decisions) and concomitantly exploring experiences of the process from professionals' and parents' perspectives. In addition, ethnicity was not specifically addressed. Exploring health decision making across different ethnic groups may be helpful, in particular the impact of culture on young people with degenerative conditions' individual attitudes, preferences and behaviours.

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