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# Can the current hypodontia care pathway promote shared decision-making?

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**Key words:**
Hypodontia, shared decision-making, preferences

## ABSTRACT

**Objective:** To determine the extent to which the current care pathway in hypodontia promotes shared decision-making (SDM)

**Design:** Exploratory cross-sectional study using qualitative methods

**Setting:** Orthodontic Department of two NHS Teaching Hospitals in Yorkshire

**Participants:** Young people aged 12-16 years old with hypodontia of any severity and at any stage of treatment, and their parents and guardians.

**Methods:** (1) Observation and audio-recording of interdisciplinary consultation in hypodontia clinics (n=5) without any researcher interference (2) Short, structured interviews with young people with hypodontia (n=8) and their parent (n=8) using a topic guide to explore themes around decision-making. Audio-recordings were transcribed and analysed using a thematic framework.

**Results:** Consultations were used as an opportunity for interdisciplinary discussion, information provision and treatment planning. Evidence of good communication was observed but patient engagement was low. The decision to be made was usually stated and treatment options discussed, but time constraints limited the scope for adequate information exchange and assessment of understanding. No methods were used to establish patient and family preferences or values. Interviews suggested parents expect the dental team to make decisions and young people rely on parental advocacy. Despite little evidence of SDM, participants reported satisfaction with their treatment.

**Conclusions:** The current care pathway for hypodontia does not support clinicians in the steps of shared decision-making. Recommendations for improving SDM processes include support to identify preference-based decisions, greater access to comprehensive and accessible patient information to enable preparation for consultation, alternative methods for effective communication of complex information and use of preference elicitation tools to aid value-driven decision-making.

## Introduction

Shared decision-making (SDM) is a collaborative process in which clinicians support patients to make decisions about their own health care given their individual circumstances (NHS Choices, 2018a). SDM is central to delivering quality patient-centred care through improvement to the patient-professional relationship developed by partnership, reduction in over-treatment and greater consistency in care (NHS Choices, 2018b). SDM communication proactively integrates three components: evidence-based practice, the clinical context, and patient preferences. It requires patients and professionals to share an understanding of the health problem, knowledge and experience about all treatment options (including no intervention), explanation of availability of options, agreement on a course of action, and negotiation to implement choice in context of the patient's lifestyle (Legare et al. 2011).

SDM is necessary at any point in the care pathway where more than one care option exists, including the option to retain the status quo. It is a multi-step process and can be described in terms of key stages (Figure 1). First, it is necessary to ensure the patient is explicitly informed that there is a decision to be made and that there is no single right choice, but that the best option will depend on individual circumstances. In some cases there may be one option that carries significantly greater risk or benefit, while in others the options may be more balanced due to clinical factors or a lack of evidence for specific treatment efficacy. In such choices, the decision is predominantly preference-based and the clinician needs to adopt a position of equipoise (Elwyn et al., 2009).

Information exchange requires comprehensive discussion of the patient's condition, all treatment options, including risks and benefits, and the supporting evidence base. The extent of discussion will be influenced by a number of factors such as the complexity of the options, patients' existing knowledge and understanding and the emotional and financial burden of the decision. Preference elicitation is fundamental to making a decision that is concordant with patient and family values. Techniques to help identify and understand preferences include value clarification methods (Pieterse et al., 2014), decision aids (BMJ, 2013) and decision counselling (NICE, 2012).

The latter stage of the decision-making process considers the feasibility of options in the healthcare setting and the personal circumstances of the patient. In the UK, there has been prominent media coverage of the so-called 'postcode lottery', where regional differences in service commissioning affect the availability of services and treatments (Which, 2018). Other factors may also determine the suitability of options, such as time requirements, resource availability, local expertise and patient factors, such as health status or social circumstances.

The scarcity of evidence of engagement in SDM in dentistry has previously been highlighted (Ryan & Cunningham, 2014; Bekker et al., 2010). Since then, reports of a new approach to interdisciplinary clinic structure for orthognathic treatment consultation to promote patient engagement (Ryan et al. 2014) and trials of decision aids for orthodontic treatment (Marshman et al., 2016; Parker et al., 2017) have been published. However, the wider application of SDM is still unclear. This study aims to explore how SDM practice is incorporated in the current care pathway for hypodontia, using a patient-centred perspective.

Hypodontia can be a complex condition requiring extensive care and collaboration across dental specialists (Hobkirk et al., 2012). Where interdisciplinary treatment is indicated, hypodontia is considered a high priority condition (Brook & Shaw, 1989) and treatment within secondary care is often warranted to allow direct liaison between team members (British Orthodontic Society, 2014). Specific hypodontia clinics have been advocated to streamline the treatment process, improve efficiency and patient satisfaction (Tams & Ashley, 2013) and provide an opportunity for agreeing treatment plans and responsibility for delivery of care (Borrie & McIntyre 2008; Crawford et al., 2010; Parvizi et al. 2010; Borrie & Cord, 2014). This study observed decision-making practice in hypodontia clinics in combination with interviews with adolescents with hypodontia and their parents to explore their perception of decision-making.

## Aim

To explore the extent to which the current care pathway in hypodontia promotes shared decision-making (SDM).

Objectives:

- To describe the current process for decision-making in hypodontia
- To appraise the use of SDM practices during consultations
- To explore adolescent and parent experience of decision-making for dental treatment for hypodontia

## Design

Cross-sectional study using qualitative methods:

1. Observation of interdisciplinary consultation in hypodontia clinics
2. Interviews with young people and parents

This study was part of a larger study examining adolescent and parent decision-making and preferences in hypodontia. It is an exploratory study to establish whether SDM in dentistry warrants further examination and if the approach of observing consultations is a suitable approach.

Ethical approval was granted by North West Lancaster Ethic Research Committee on 15th October 2015 (Study reference 15/NW/0804). Approval was granted from the Research and Development department at each participating site.

## Setting and sample

The study was undertaken in the Orthodontic Departments of two NHS Teaching Hospitals in Yorkshire. These hospitals serve a diverse population in terms of ethnicity, socioeconomic status and general and oral health. The researcher (SB) attended hypodontia clinical consultations in other units in England to gain understanding of the care pathway and to observe any similarities or differences in practice that may influence the generalisability of observations. The units visited represented a convenience sample and observations demonstrated consistency in referral processes and approach for delivery of care.

The target population included adolescents (aged 12-16 years old) with hypodontia of any severity and at any stage of treatment, and their parents and guardians. Adolescents with craniofacial conditions or significant medical histories were excluded if their condition was judged to potentially impact on treatment options or provision of care. Participants were not excluded based on language but for feasibility reasons, only the English component was transcribed and analysed. Purposive sampling was used to select participants based on severity of hypodontia, stage of treatment, age and gender. For the observation of clinical consultations, all dental professionals present were invited to participate and consent obtained from clinicians for observation and audio-recording. Transcription and data analysis were undertaken contemporaneously to identify data saturation, judged to be the point where no new themes were emerging.

## Methods

1. Observation of clinical consultation

The first part of the study involved naturalist observation of clinical consultations between the dental team, adolescents with hypodontia and their parents. Potential participants were identified during clinic preparation and approached on the day of the appointment. The researcher provided verbal and written information about the research. If willing to participate, consent was obtained from the young person and parent and anonymous basic demographic data was collected including age, sex, number of missing teeth and presentation of hypodontia, stage of treatment and relationship of accompanying parent. The entire consultation was audio-recorded using a digital voice recorder and external microphone by one researcher (SB) without any interference. Clinicians were encouraged to follow normal consultation procedures.

2. Interviews with young people and parents

The second stage of the study involved semi-structured interviews with adolescents with hypodontia and their parents. Potential participants were identified by the direct clinical care team and given verbal and written information about the research. If agreement was given, the researcher contacted the parent 1-2 weeks later to confirm participation. Any reasons given for declining to participate or withdraw for the study were noted. Consent was obtained from the young person and parent at the time of interview. Interviews were conducted in a private room in the hospital orthodontic department where the participant received their usual dental care. A topic guide was used to prompt discussions consistently across interviews but with flexibility for participants to discuss experiences of relevance to their lives. The topic guide covered was devised with input from a decision-making expert (HB) and patient representatives and covered three domains: understanding of hypodontia, management and decision-making (supplemental file). The first part of the interview included the young person only; the parent was invited to join for the latter part of the interview and the same topics were revisited. The interview was audio-recorded using a digital voice recorder and external microphone.

## Analysis

Recordings were transcribed into Microsoft Word v14.7.7 and anonymised. The transcripts were analysed using the framework analysis method (Ritchie & Spencer, 1994). Dialogue was divided into meaningful units then similar units were grouped to develop themes & subthemes. The units and developing themes were discussed independently with HB, a decision scientist with extensive experience of qualitative data analysis. The data were classified into themes and subthemes. The analytic framework was refined through discussion with all authors prior to finalisation. The results were synthesised to address the study objectives using a narrative approach with supporting quotes that are typical to the theme.

## Results

Data collection was undertaken from August 2016 – August 2017. Demographics of the participants for both methods are given in Table 1. In the study period, no adolescents at the end of treatment attended for a multidisciplinary consultation, so observations were limited to those at the start of treatment or in active treatment. The interviews included adolescents at all stages of treatment. Generally, those nearing the end of treatment were more familiar with treatment processes and terminology, however, their perception of their role and experience in decision-making did not differ notably from those at the start or mid-treatment.

The observation of clinical consultations included 5 participants. This number is lower than was expected a priori due to identification of standardisation in the clinical approach. Standardisation in consultations is advocated as a means for reducing variation in practice and improving the quality of care (Lavelle et al., 2015), however, this meant a similar pattern was seen in all consultations leading to rapid data saturation. For the interviews, eight adolescents and eight parents were involved. This provided sufficient information to support the observations from the clinical consultations for the purpose of this exploratory study.

### Consultation process

Patients attended the interdisciplinary hypodontia clinic at different treatment stages including pre-treatment, mid- or near-end of orthodontic treatment for re-evaluation of space distribution and post-orthodontic treatment for restorative treatment planning. The consultations had three main purposes:

i) Information exchange between the dental team, patient and family
ii) Inter-professional discussion amongst the dental team
iii) Decision-making and treatment planning

Confirmation of a final treatment plan depended on the stated purpose of the clinic. In one unit patients were provided with information and offered the opportunity to consider their options before returning to their referring clinician to confirm the treatment strategy, while in the other unit a treatment plan was agreed in the consultation. The time point for agreeing a treatment decision appeared to be dependent on the hospital care pathway rather than patient circumstance.

A pre-clinic meeting involving dental team members was used to discuss cases and formulate possible treatment plans. Dialogue within the consultation was largely inter-professional discussion and information provision from dental professionals to the parent to facilitate understanding of the condition and treatment options. Parental contribution was predominantly confirmation of the accuracy of patient information while adolescents contributed little other than to outline their concerns and symptoms. The allocated 20-30 minutes for consultation was fully utilized in all cases observed, yet this was frequently insufficient time to cover all information needs, particularly for pre-treatment patients attending for treatment planning who reported having little information prior to their appointment.

Good communication practices were observed throughout the consultations, such as introduction by team members, use of child-friendly language, non-dental examples and props to improve explanations, humour to alleviate anxiety and multiple opportunities for parents and young people to ask questions. Individual factors such as medical history, age, dental health and oral hygiene were integrated into the consultation to personalise the treatment options and the feasibility of treatment delivery in different services were discussed.

### Shared decision-making practices in the consultation

Dialogue was classified under three themes related to the stages of decision-making: i) Decision to be made; ii) Information exchange; iii) Preferences and values.

i) Decision to be made (Box 1)

The decision was explicitly stated in most consultations, often with an indication of time scale and acknowledgement of the complexity of the decision. The option of more than one treatment, including no treatment, was routinely highlighted. The option of no treatment was not explained as an active choice with physical and quality of life implications that would require some degree of adaptation and self-care. In most cases, the clinical presentation and lack of evidence for specific treatments meant treatment decisions were ones of clinical equipoise, where it would be appropriate to elicit patient preferences when choosing the best option for the patient.

ii) Information exchange (Box 2)

Information was provided about the individual’s clinical presentation and treatment options with some discussion of potential risks and benefits and the impact of treatment. Information leaflets were often provided to supplement the information provided verbally. Clinicians attempted to elicit patient understanding but there was often little engagement from the patient and no methods for testing understanding were used. There was evidence that parents were unfamiliar with dental language and there were deficiencies in knowledge of treatment options and process. Evidence-based estimates of treatment efficacy were provided for some treatments but generally scarcities in high quality evidence and a lack of patient-centred methods for explaining research data were reported to be a barrier to further comparison of treatment efficacy.

iii) Preferences and values (Box 3)

Little dialogue in the consultation was attributed to elicitation of patient and family preferences and values. The impact of hypodontia and motivation for treatment were sought during the consultation, most commonly in terms of physical outcome from treatment. Although references were made to the importance of preferences in the decision, no tools were employed prior to or during the consultation to assist identification of patient and family values and preferences. In one consultation a parent expressed a preference for a specific treatment but in the remaining observations no treatment preferences or general values for aspects of treatment were given.

## Adolescent and parent perception of decision-making

Analysis of the interviews identified five themes related to the stages of decision-making: i) Roles in decision-making; ii) Treatment options; iii) Understanding; iv) Preferences; v) Satisfaction with the decision.

### i) Roles in decision-making (Box 4)

Parents largely perceived the decision-making process to be led by the dental team, with their role being to support their child to ensure the treatment selected was appropriate. This was reflected by adolescents who indicated an advocacy role of parents, and to a lesser extent the dental team. Parents and adolescents did not appear to perceive their role in determining their level of involvement in decision-making.

### ii) Treatment options (Box 5)

Recall of the treatment options given during treatment planning was variable. The option to have no active intervention was commonly dismissed by adolescents, who reported a strong desire for treatment.

### iii) Understanding (Box 6)

Participants reported variable understanding about treatment options and there was evidence of misunderstanding even for those near the end of treatment. For some treatments, participants sought additional information from other sources, most commonly the internet, and expressed a desire for evidence-based information about treatment efficacy.

### iv) Preferences (Box 7)

When treatment preference was discussed, participants referred to their motivation for treatment and expectation of treatment outcome, most commonly in relation to physical outcome or wellbeing related to dental appearance. There was no discussion regarding the use of decision aids or value clarification methods. It appeared previous information provision about treatment options had resulted in formation of beliefs about certain treatment options, most commonly dental implants, that may not accurately reflect the evidence base. Interestingly, participants nearing or at the end of treatment were more able to understand their own willingness to accept treatment side effects (pain) for improved outcome.

v) Satisfaction with decision (Box 8)

Participants were generally satisfied with their experience of treatment, however, there was little reflection on the experience of decision-making and satisfaction with the choices that were made. One participant near the end of treatment highlighted how her willingness to accept the treatment decision changed over the treatment period, suggesting an initial dissatisfaction with the treatment choice.

## Discussion

The results of this study indicate that the current care pathway for hypodontia does not promote SDM for a number of reasons; patients' lack of awareness of the decision to be made and all possible options, limited knowledge of patients' preferred level of participation in SDM, lack of information exchange to enable meaningful discussion and absence of patient preference and values. The challenges to SDM appeared to arise from low patient involvement, a lack of awareness, education, training and support for clinicians and limitations in the organisational structure of the care pathway.

SDM requires an explicit statement of the decision to be made and identification of patients and families desired role in decision-making. Interdisciplinary clinics are perceived to be an opportunity for making decisions about treatment (Tams & Ashley, 2013), yet participants were not able to identify their preferred level of involvement in SDM. Observations indicated discussions were more around processes and indicating which member of the clinical team were responsible and accountable for specific components of care. Low patient involvement is often assumed to mean patients do not wish to make decisions, however, there is evidence from the dental setting that in many circumstances the preferred level of participation is higher than the perceived level (Chapple et al., 2003). Integrating prompts and decision aids has been shown to increases involvement and decisional experience (Hubner et al., 2018), which in turn increases satisfaction (Gravel et al., 2016).

Low engagement in SDM from a patient perspective most commonly arises from a lack of knowledge about the decision between options, an inability to communicate effectively and not feeling empowered to participate (Sullivan et al., 2017). It is reasonable to assume most people will want the best possible outcome with least cost and inconvenience, however, it is necessary that the outcomes of treatment and procedures required to achieve these are understood. There was evidence of misunderstanding of dental procedures and unfamiliarity with dental terminology in both the consultations and interviews despite much of the consultation being used to deliver information. Previous work has identified limited high quality, comprehensive patient information resources to allow patient preparation for consultation (Barber et al., 2018a) and this, alongside absences in the evidence base and a lack of patient-centred outcomes (Barber et al., 2018b) presents issues for effective information exchange.

Hypodontia treatment is, in many cases, a preference-sensitive decision due to the absence of a single 'best' treatment. Establishing patient and family preferences is fundamental to providing the most appropriate care. Patient concerns and motivation for treatment were used as an indicator of expected treatment outcome but no tools or techniques were employed to help patients and families understand their own values and preferences. The absence of preference elicitation methods is a result of a lack of available tools, low clinician awareness of SDM processes and a lack of training in preference elicitation. Decision-making aids have been developed and tested in areas of dentistry (Marshman et al., 2016; Parker et al., 2017; Johnson et al., 2006; Park et al., 2012) but preference elicitation tools have not yet been integrated into routine clinical practice. Failure to help patients identify their priorities presents challenges for integration of care into patient and family lifestyle and for planning of future care. Clarification of values and preference may help patients to understand their own willingness to accept treatment risks, side effects or inconveniences in treatment delivery to achieve their desired outcome while those who are inadequately informed and prepared may report dissatisfaction with choices and poor adherence to treatment (Joosten et al., 2008; Alzahrani & Gibson, 2018).

The absence of SDM mechanisms is also a consequence of organizational limitations (Sullivan et al., 2017) in the current care pathway, such as limited time for consultation appointments, limited number of visits allocated for decision-making, and conflict between SDM and clinical guidelines or referral pathways. Integration of SDM into care requires a change of attitude and behavior at all levels to make SDM an organizational priority that aligns, rather than competes, with other demands (Joseph-Williams et al., 2017). Changes can be more straightforward to implement, such as introduction of a 3-question prompt to promote SDM to patients, or more complex, towards a reorganization of the care pathway to incorporate specific SDM steps and appropriate training and support (Health Foundation, 2013)

A number of recommendations for incorporating SDM principles into hypodontia care are given (Table 2). These include relatively straightforward changes that could be applied within the current interdisciplinary care pathway to promote SDM alongside more complex changes that require additional research and development of resources. This study highlights the need for further research to identify barriers to integration of SDM into routine practice and to inform the development of SDM tools.

The main limitation of this study is the relatively low number of participants, however, there is evidence that the approach to care has been standardised and informal observation of consultations more widely indicated a similar pattern. The study was an exploratory study conducted in one geographical area; it would be interesting to observe decision-making processes both more widely in hypodontia, and in other interdisciplinary conditions to allow triangulation of the findings and to strengthen the recommendations made. Measurement tools for examining SDM have been suggested (Gartner et al., 2018) and future research may benefit from an objective, standardised approach to measuring SDM practice. It would also be interesting to observe and interview the same participants to directly compare observed practice and the lived experience of young people.

## Conclusions

The current pathway for hypodontia does not promote SDM due to low patient involvement, clinician's limited awareness and training in SDM, an absence of support tools and organisational barriers. Adolescent patients and their parents demonstrated inadequate knowledge about hypodontia and its treatment, and a lack of unawareness of their role in SDM. A shift in the approach to incorporating SDM into the care pathway will support clinicians to deliver patient-centred care; this requires greater patient involvement through clinician training for SDM, improved information provision to address knowledge gaps and skills, tools and support to aid preference identification.

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