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Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies

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Abstract

Objectives—We aimed to (i) explore how health professionals and managers who work with young people seek to define developmentally appropriate healthcare (DAH), (ii) identify the range of conceptual dimensions present in their definitions and (iii) explore the controversies embedded in their characterisations of DAH.

Methods—A qualitative multisite ethnographic study was conducted across three hospitals in England. We undertook face-to-face semi-structured interviews with health professionals and managers; and non-participant observation in clinics, wards and meetings. Anonymised field notes and interview transcripts were analysed using thematic analysis. The theme 'conceptualisations of DAH' was then further analysed, and the resulting themes categorised to form conceptual dimensions.

Results—We recruited 192 participants and conducted 65 interviews (41 with health professionals and 24 with managers) and approximately 1600 hours of non-participant observations (involving 103 health professionals and 72 managers). Despite the wide range of definitions provided by participants, five conceptual dimensions of DAH were identified: (i) biopsychosocial development and holistic care, (ii) acknowledgement of young people as a distinct group, (iii) adjustment of care as the young person develops, (iv) empowerment of the young

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person by embedding health education and health promotion and (v) interdisciplinary and interorganisational work. Also, some controversies were identified within most dimensions.

Conclusions—This study illustrates the lack of a generalised definition of DAH for young people among UK health professionals and managers, and presents a set of five core dimensions that can inform future research to help define and evaluate DAH for young people.

Introduction

The increasing knowledge surrounding adolescent and young adult development[1 2] offers opportunities to develop and reshape healthcare services to better meet the biopsychosocial developmental needs of adolescents and young adults (AYAs). Approaches that draw on young people's perspectives such as youth-friendly healthcare (YFHC) indicators[3] are essential to develop appropriate and meaningful services for AYA. However, it is equally important to develop a shared understanding among health professionals (HPs) and managers (MAs) about the key principles underpinning the practice of AYA-centred healthcare so that services are consistent, well understood and recognised in and across organisations. Developmentally appropriate healthcare (DAH) for young people, which has been described as a key principle underpinning the practice of adolescent medicine,[4 5] may be particularly well suited to serve this purpose.

DAH for young people is care that acknowledges the dynamic impact on health and ill-health of the biological, psychological, social and vocational development of young people. For example, YFHC for a 13-year-old will thus look very different to care for a 23-year-old or for another 13-year-old.

The focus of DAH is therefore an approach to clinical work with AYA, which conveys the dynamic nature of AYA development (rather than chronological age) as a defining characteristic of health services, and offers room to achieve consistency in clinical practice regardless of whether adolescent medicine is recognised as a distinct specialty or not in a particular context.

However, the need for a shared understanding among HPs and MAs does not preclude the importance of young people's perspectives. Thus, DAH should not be seen as an alternative to YFHC but as an addition of new elements and perspectives to the current debates on healthcare provision for AYA. Furthermore, DAH and YFHC can be combined to provide health services that are youth friendly and developmentally appropriate, meaningful and consistent from both the AYA and provider perspectives.

This paper reports specific findings from a broader study exploring the factors affecting the implementation of DAH for AYA in hospital settings. In this paper, we aim to (i) explore how HPs and MAs who work with AYA in hospital settings seek to define DAH, (ii) identify the range of conceptual dimensions present in their definitions and (iii) explore the problems or controversies embedded in their characterisations of DAH.

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Methods

A qualitative multisite ethnographic study[6–8] was conducted across three hospitals in England (a district general, a paediatric tertiary and an adult tertiary hospital). This formed part of a larger research programme.[9 10] The hospitals were chosen as they all have a history of championing research and innovative service provision for AYA but did not have dedicated organisation-wide AYA healthcare nor AYA-dedicated wards other than for teenage cancer.

HPs—including doctors, nurses and allied HPs—were recruited through six medical and surgical specialties chosen to represent the heterogeneous services found in UK National Health Service hospitals: general paediatrics, rheumatology, diabetes, trauma and orthopaedics, emergency care and outpatients. In addition, some HPs were recruited during the course of the study through other specialties (endocrinology, cardiology, oncology and respiratory), departments (radiology, psychology, youth work and chaplaincy) and settings (training sessions).

MAs were recruited at each site when their roles were relevant to the provision of services for AYA in paediatrics and/or adult care. Participants were classed as MA or HP based on the main focus of their work; many of the MAs also had a clinical workload or were clinically qualified.

Data were collected between June 2013 and January 2015 by AF and VW (who had no prior involvement at the participant sites). During this 20-month period, we conducted face-to-face semi-structured interviews with HP and MA across the three participant organisations and non-participant observation in clinics, wards and meetings where HP and MA were involved. Participants were purposively sampled, initially through maximum variation sampling and then refined through snowball and theoretical sampling, until saturation was considered to be achieved. Information sheets detailing the project were provided to all participants and written consent for interviews and observations was taken after a period of at least 24 h.

Anonymised field notes and interview transcripts were then analysed using thematic analysis[11 12] assisted by QSR NVivo V.10 software. Data collection and analysis was iterative. We employed a range of strategies including triangulation (between-method, investigator and data sources), respondent validation, multiple coders and expert validation.

To examine the specific question of how DAH was being understood and defined in hospital settings, we undertook further focused analyses. The theme 'conceptualisations of DAH', which included relevant field notes and interviews, was set aside and then further analysed. Interview data were coded and observational data were used to inform coding framework and data interpretation. Results were summarised into a concept map for team discussion, which informed further iterations of data analysis, refinement and discussion.

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Results

A total of 192 participants were recruited (table 1). In total, 65 interviews (41 with HP and 24 with MA) and approximately 1600 hours of non-participant observation (involving 103 HP and 72 MA) were conducted. Some individuals participated in more than one interview or observation.

Participants found it difficult to define DAH; the definitions showed considerable variability and were often preceded by expressions of uncertainty (table 2, quote 1).

The participants' process of outlining the features and elements of DAH was often done by omission, that is, by establishing what DAH is not. They often emphasised its contrast with generalised, well-established practices (table 2, quote 2). As such, DAH was rarely positioned as a concrete set of practices that people were currently involved in providing. It was also associated with a change in the current provision of services (table 2, quote 3).

In some cases, participants did not recognise DAH as a concept (table 2, quote 4), were unable to offer any specific ideas (table 2, quote 5) or were unable to provide a definition (table 2, quote 6).

A core set of five conceptual dimensions was identified across the definitions (table 3) and descriptions of DAH that participants provided. However, some controversies were also identified within most dimensions.

Bio-psycho-social development and holistic care

DAH was considered to revolve around adolescent development and the assumption that development occurs at biological, psychological, social and vocational levels (table 2, quote 7). Participants noted that DAH involves taking all these aspects into consideration by adopting a 'holistic' approach, which looks beyond the physical aspect of one's condition and incorporates the family or trusted others (table 2, quotes 8–10).

However, the adoption of a holistic approach to clinical work was disputed. The majority advocated an approach that integrates the biological and psychosocial aspects of development (table 2, quote 11). Others believed that medical work remained unchanged (table 2, quotes 12–13) and regarded DAH as an *addition* to medical work or about managing the physical environment for AYA.

Acknowledgement of AYA as a distinct group

At a clinical level, DAH was associated with particular ways in which professionals interact and communicate with their patients in terms of what, when and how information is given to and gathered from them (table 2, quote 14).

At a managerial level, DAH was seen as influencing communication with the AYA at a broader level (table 2, quote 15) and associated with acknowledging AYA as a distinct group for which specific services and spaces are provided within the hospital setting (table 2, quote 16). Likewise, acknowledging and addressing the needs of professionals looking after AYA was also considered important (table 2, quote 17).

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Adjustment of care as the young person develops

Since the provision of DAH is dependent on the stage of development of the young person, it has to be assumed that the practice of DAH is dynamic in nature (table 2, quote 18).

The starting point of DAH consists of carrying out a developmental assessment, which covers all the areas of adolescent and young adult development, and actively involves families and/or trusted others (table 2, quote 19).

Such assessments will then inform particular aspects of service delivery, which will be tailored to the individual patient (table 2, quote 20).

Empowerment of the young person by embedding health education and health promotion

HPs expressed that their roles include providing informal education to the young person on a variety of AYA health issues and self-management skills (table 2, quotes 21 and 22).

Thus, DAH is about empowering AYA by effectively giving them relevant information at every stage and teaching them self-management skills, which in the particular case of AYA with chronic conditions may often revolve around a transition agenda (table 2, quote 23).

However, some raised the question of whether health education always, automatically, empowers the patient (table 2, quote 24). Empowering the young person was not considered to be about health education per se, but about a conscious approach to health education that promotes active engagement and autonomy enabling practices without creating relations of dependency.

Interdisciplinary and interorganisational work

The holistic and patient-centred nature of DAH relates to another important aspect of DAH: the teamwork dynamics that make it possible (table 2, quote 25).

At a managerial level, a necessary consideration is that DAH involves effective coordination, consistency and joined-up working across specialties and even across organisations, including the often less visible pathways of those patients who will not go to an adult provider (table 2, quote 26).

Alongside this, the fact that within the UK organisational context there are clear age cut-off points set for moving between paediatric and adult services may lead to institutionally rather than developmentally driven transitions and create additional challenges to implement DAH in practice both in paediatric and adult-based services (table 2, quote 27).

Discussion

DAH has been described as a key principle underpinning the practice of adolescent medicine[4] with preventive healthcare and transition to adult healthcare being integral but different conceptual approaches that assist clinical implementation of DAH for AYA.[5]

The finding of a *lack of a generalised definition of DAH* among HPs and MAs, alongside the wide range of definitions provided, is consistent with our previous work on the use of the

term DAH in the literature.13 The fact that not all the dimensions were necessarily present in every definition, together with the elements of dispute identified, illustrates the plurality of understandings that coexist among practitioners. While some participants conceive DAH as a fundamental principle that impacts on all aspects of clinical work with AYA, others just define DAH by one of its components. However, we did identify five, interrelated, dimensions of DAH across the definitions and descriptions of DAH that participants provided.

The *biopsychosocial development and holistic care* element of DAH is in line with a growing body of evidence on brain development,14–16 the psychosocial impact of puberty and pubertal timing17–20 and the inter-relatedness of biological, psychological and social development in the context of chronic illness.21 Also, the provision of holistic care and the dynamics of involving parents and/or significant others in care provision are important topics in adolescent health literature.22 23

Acknowledging AYA as a distinct group is an element that relates to well-researched aspects of adolescent health such as communication issues and environmental issues, both well-grounded and represented in initiatives that draw on AYA's perspectives.3 24 25 Beyond that, the issue of professionals' recognition within the context of their organisations has received less attention.26 However, having the specific needs of professionals looking after AYA identified and addressed, even if it is just from identifying the unmet training needs,27 may be a key step towards acknowledging AYA as a distinct group in an organisation. This could be particularly important for professionals working in countries where adolescent and young adult health is not a recognised distinct specialty, as in the UK, to support and make visible their work.28

The *dynamic nature of DAH* relates to its core logic, that is, the fact that DAH is informed by biopsychosocial development29–34 and then delivered in a tailored fashion within a flexible and responsive service.35 Continuous developmental assessment will set the pace and intensity of the care provided and help HPs maintain awareness of adolescent development in their interactions with the AYA and their parents.4

Empowering the young person entails incorporating informational and educational goals in healthcare provision,34 in line with an individually defined health education and transition agenda,5 and integrating their health and disease management into their overall life projects in order to achieve a high quality of life.36

The *teamwork* dimension of DAH highlights the 'joined-up' and interdisciplinary nature of young-people-centred healthcare services at clinical and organisational levels.24 This is particularly due to the fact that most of the AYA will move into adult settings and also because of the often less visible pathways of those AYA referred back to their community-based healthcare services or discharged from a short stay or following emergency care. However, the fact that it is difficult for a single clinician to tackle all aspects of AYA's health22 may in itself explain the presence and relevance of teamwork in the conceptualisation of DAH.

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HPs and MAs discussed DAH often in terms of hopes and expectations about future service provision. The five dimensions of DAH (table 3) identified were seen as current routine practice solely in small discrete areas, and the implementation of DAH was very uneven across the organisations.

The holistic nature of DAH and its implications for clinical practice may be challenged by a core tension between DAH as an *integral approach* to healthcare and DAH as an *addition* to the medical components of care. Therefore, it is not clear whether it is assumed that the physical, psychosocial and vocational aspects of adolescent development remain intertwined to form an integrated approach to service delivery; or whether the environmental, psychosocial and vocational aspects of DAH are addressed alongside medical work but independent from it. However, the interdependence of psychosocial and cognitive development on the physical and biological development and vice versa would be further support of an integrated approach.17

Limitations and Strengths

Although there is a body of work surrounding YFHC, we have found no other studies employing ethnographic methods to specifically explore DAH for AYA in hospital settings. The selection of ethnographic methodology is a major strength of the study as it facilitated the immersion of the researchers into the organisational culture of each hospital, enabling them to observe and examine the process and practices in context. A limitation was that only three sites in two UK regions were studied. However, a significant number of staff participated and a wide range of settings were encompassed including outpatient, inpatient and emergency care as well as medical and surgical specialties. Furthermore, although the hospitals involved had a history of championing research and innovative service provision for AYA, this did not include a defined adolescent medicine service and participating areas and/or specialties were at different stages of familiarisation with providing DAH, thus providing the study with breadth and depth of experience. Similar work in a comparator group of hospitals who did not have the same history would be of interest. Other limitations, such as the UK scope of the study, the hospital-based (non-community) sampling of professionals and the cultural dimensions of the DAH concept, should also be addressed in future research.

Conclusions

This study illustrates the lack of a generalised definition of DAH, one of the key principles underpinning the practice of adolescent medicine, among HPs and MAs in the UK. Its findings suggest that, despite the wide range of definitions provided by participants, there is a set of five core interrelated dimensions of DAH that can be identified across such range of definitions. The results can help provide a foundation to evaluate whether healthcare services are delivering DAH to AYA, and this is an area that we intend to follow-up by using these findings to inform the design of a Delphi study37–39 involving experts from the field in order to achieve formal consensus on the content and range of a definition of DAH for AYA at both conceptual and operational levels.

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What is already known on this topic

- The provision of consistent, coordinated healthcare during adolescence and young adulthood has been reported as a key issue impacting upon young people's biomedical outcomes and engagement with healthcare services.
- Developmentally appropriate healthcare is considered a key principle underpinning the practice of young-person-centred healthcare, responsive to the evolving developmental status of adolescents and young adults.
- Previous research revealed that no agreed formal definition of developmentally appropriate healthcare is available in the literature and that the term is being inconsistently used.

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What this study adds

- By examining how health professionals and managers in three hospitals defined developmentally appropriate healthcare, we identified the core issues of this concept from their perspective.
- Care responsive to biopsychosocial development, empowerment of the young person and acknowledging young people as a distinct group across departments and organisations were key aspects.
- Findings from this study can inform future research to help define and evaluate this approach to clinical work.

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Table 1

Participants recruited for the study

	District general hospital	Paediatric tertiary hospital	Adult tertiary hospital	Total
Participants interviewed				
Health professionals	13	18	10	41
Managers	13	6	5	24
Total	26	24	15	65
Participants observed				
Health professionals	65	27	11	103
Managers	57	0	15	72
Total	122	27	26	175
Overall participants				
Health professionals	78	45	21	144
Managers	70	6	20	96
Total	148	51	41	240
Number of participants who were both interviewed and observed	39	5	4	48
Total number of participants	109	46	37	192

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Table 2

Illustrative quotations from participants

Quote 1	"The problem is that you can't define it [DAH] I think easily (…) So it's very, very difficult as you can see from me trying to explain". (HP 1, paediatric hospital)
Quote 2	"'I think in this Trust we provide excellent care. But again, we look at the disease specific, or injury specific care". (HP 2, paediatric hospital)
Quote 3	"How many people mentally assess teenagers and see what stage they are at (…) I don't think we are very good at checking and assessing". (HP 3, general hospital)
Quote 4	"I don't, I don't know, I've never thought about it [providing health care for young people] in that sense before I suppose". (MA 1, general hospital)
Quote 5	"When you use that word [DAH] I don't know what it means". (MA 2, general hospital)
Quote 6	"How do I define developmentally appropriate healthcare? I don't know how I would define it". (HP 4, paediatric hospital)
Quote 7	"It [DAH] would be some awareness and issues for young people in society and young people as a kind of developmental stage around things like mental health, sexual health and confidentiality, consent, drugs and alcohol, all of those things might be issues for them… Vocational issues…So it's sort of seeing that young person in that wider context I think". (HP 5, adult hospital)
Quote 8	"[DAH is] a service that looks beyond the physical injury (…) Being aware of the right questions to ask. And to look at the patient's whole journey, rather than just this episode in the patient's journey. I think to provide holistic care for the patient. You have to be aware of the family dynamics, of their social dynamics". (MA 3, adult hospital)
Quote 9	"It's [the provision of DAH for young people] about responding to their needs (…) and also involving the family or carers or whoever has come with them". (HP 6, paediatric hospital)
Quote 10	"I think developmentally appropriate healthcare only works when it's within the context of respectful, individualised healthcare anyway (…) and therefore you're always focused on that individual as well as their family". (MA 4, general hospital)
Quote 11	"The psychosocial [development] impacts on the biological [development] and the biological impacts on the psychosocial". (HP 7, paediatric hospital)
Quote 12	"Healthcare in the strictest sense, in terms of clinical healthcare, I think that remains unchanged". (HP 1, paediatric hospital)
Quote 13	"Whether they're clinically, whether they are 2, 12, 22…it makes no difference, you treat… you're there to treat their medical condition". (HP 8, paediatric hospital)
Quote 14	"You've got to be developmentally appropriate in terms of your communication, in terms of your ability to be seeing, to be listening and to be able to appropriately respond and to acknowledge what their concerns are". (HP 1, paediatric hospital)
Quote 15	"I don't necessarily think the information is very blanket, it's not always appropriate. I don't think we probably use a lot of the media social networking sites and other things to communicate with the younger person as much as we can". (MA 6, adult hospital)
Quote 16	"[DAH] is for them to have a defined space that is their defined space where there are nurses and clinicians that understand that they're stepping into an environment that is different to the adult space". (MA 5, adult hospital)
Quote 17	"I think the mind-set is different. (…) They change their approach to look after someone very elderly who's fairly sudden; it's fairly obvious they're elderly. And so, they all have had lots of training on that. We don't train people [to look after young people]". (MA 5, adult hospital)
Quote 18	"It never stops changing. That's the challenge. (…) you see one person one time, and then three months' later (…) some other developmental concern has taken primacy". (MA 7, general hospital)
Quote 19	"That assessment process is also an honest evaluation with families and with the young person about what they're capable of and what they could be capable of given a bit of a push, a bit more resourcing, a bit of encouragement, a bit of trial and error". (HP 9, paediatric hospital)
Quote 20	"[DAH is] to deliver care that is developmentally appropriate for each individual person as they're coming in to whether it would be a clinic setting or an inpatient setting, so that's best aimed. You know, if they are developmentally a four year old but they have a body of a fourteen year old, well you have to deal with both the medical side of that and the holistic rest of that side with that young person". (HP 10, paediatric hospital)
Quote 21	"It feels a bit like a gentle educational role. And you do have to be quite gentle, and to sort of not step on toes really. And to sort of try and highlight those sort of areas that do need exploring". (HP 11, paediatric hospital)
Quote 22	"The more information that we give to them helps them to develop their own healthcare really, doesn't it? (…) So I would say information giving is a massive thing in the process of development". (HP 4, paediatric hospital)
Quote 23	"Another part of developmentally appropriate healthcare is that you assist the young person to prepare and plan for the move, so you do that consciously (…) to help them realise and to help them to take responsibility, to some extent, for the move from children's to adult services". (MA 8, general hospital)

Quote 24	"For a lot of them, we seem to be fostering quite an unhealthy dependence on us. And we've seen that with feedback (…) we've done too much for them. (…) Sometimes, it's very hard to step back and we are fostering that dependence on us as an establishment". (HP 12, paediatric hospital)
Quote 25	"The integrated nature of that [psychosocial and medical needs] and the interconnectivity of those disciplines [that address psychosocial and medical needs] works most effectively for the holistic needs of those young people when that is joined up (…) where that multidisciplinary working is not just a knot but actually is effective and that there is understanding and respect across the multidisciplinary and security to make referrals across multidisciplinary working". (HP 13, paediatric hospital)
Quote 26	"It's [joined-up working] within certain specialties (…) where they work across the different sites. And they've got quite clear guidance on what the adult services expect and how they function. But for us, for the general medical patients, there isn't that… some might not even go to an adult provider. They might just go to the GP". (HP 12, paediatric hospital)
Quote 27	"Whether they are ready developmentally or not, it's sort of an age in this hospital I'm afraid and it always will be, because they have to go by the time they are eighteen regardless". (HP 14, paediatric hospital)

HP, health professional; MA, manager.

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Table 3
Conceptual dimensions of developmentally appropriate healthcare for young people

1	Biopsychosocial development and holistic care
2	Acknowledgement of young people as a distinct group
3	Adjustment of care as the young person develops
4	Empowerment of the young person by embedding health education and health promotion
5	Interdisciplinary and interorganisational work