



University of Dundee

Transitional care

McDonagh, Janet E.; Farre, Albert

Published in:
Nature Reviews Rheumatology

DOI:
[10.1038/s41584-022-00836-x](https://doi.org/10.1038/s41584-022-00836-x)

Publication date:
2022

Document Version
Peer reviewed version

[Link to publication in Discovery Research Portal](#)

Citation for published version (APA):
McDonagh, J. E., & Farre, A. (2022). Transitional care: time for a rethink? *Nature Reviews Rheumatology*, 18(11), 615-616. Advance online publication. <https://doi.org/10.1038/s41584-022-00836-x>

General rights

Copyright and moral rights for the publications made accessible in Discovery Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from Discovery Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain.
- You may freely distribute the URL identifying the publication in the public portal.

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Clinical Practice

Transitional care: time for a rethink?

Janet E. McDonagh and Albert Farre

Standfirst

Transitional care in rheumatology has been debated for over three decades and yet unmet needs of young people are still being reported. Why the slow progress? Perhaps we need to stop talking about transitional care in rheumatology and talk more about developmentally appropriate healthcare for young people with rheumatic conditions.

Refers to Carandang K et al. Adolescents' and young adults' recommendations for implementing healthcare transition in rheumatology: a mixed methods study. *Arthritis Care Res.*

<https://doi.org/10.1002/acr.24977> (2022)

Main text

One of several transitions experienced by young people growing up is in health care when young people move from child to adult-centred services. Transitional care can be defined as the process of preparing the young person and their caregivers for this transition and is particularly pertinent for young people with rheumatic conditions that persist in adulthood. Carandang and colleagues present the results of their research¹, which focussed on what young people think about the implementation in rheumatology of the Six Core Elements of Healthcare Transition, a nationally funded model of health-care transition in the USA. The young people clearly approved of the content of this model and also provided useful insights and suggestions for how to better translate the model components into practice. But should we start thinking about the rheumatological care of young people in a broader context rather than just focussing on the health transition?

The three key themes identified from the qualitative analysis of the focus group data — namely, implementation of a structured education care plan, empowerment of young people and consideration of the parental role¹ — reflect the existing international guidance², with the latter two themes having been subsequently shown to be associated with positive outcomes³. Why then are young people reporting the need for further attention to these issues to ensure implementation in actual practice? As Carandang and colleagues remind us¹, transitional care in rheumatology has been discussed in the literature for over three decades⁴. We would propose that we actually need to stop talking about transition and rather listen to the young people who, as noted in this study¹, want to “learn to live with a chronic illness” and “contextualize health-care transition within other life milestones”, that is, not just learn about transition per se.

Adolescence and young adulthood is characterized by multiple transitions — biological, educational, social, vocational as well as health-related transitions — all of which are interdependent and need to be acknowledged by rheumatology health professionals. Perhaps it is time to shift the mindset and first and foremost think of our patients as young people who are learning to manage their health as well as their rheumatic condition as they are growing up. Rather than thinking of health transition as a crisis that takes centre stage relative to other life transitions, we should start talking about this transition as another developmental milestone and consider providing developmentally appropriate health care rather than just transitional care. The former, by definition⁵, would address the health implications of all the various life transitions as well as all the issues raised by the young people in this latest study¹.

The need for developmentally appropriate communication is highlighted several times by the young people involved in this study and probably reflects, at least in part, unmet training needs of health professionals in this area^{6,7}. The young people clearly desire the rheumatology professionals to discuss

the classic adolescent triad of sexual and reproductive health, substance use and mental health in rheumatology clinics, but the question remains as to whether the rheumatology professionals are competent to discuss these topics in both a developmentally appropriate as well as an effective way. Research has shown a discrepancy between what the health professional perceives has been discussed and what the young person actually takes in, particularly with these more sensitive topics⁶. Results from a systematic review highlight how the communication between health-care professionals and young people can influence health outcomes⁷ and the importance of confidential time for young people as well as the changing role of the parent as the young person gets older, which are the very issues raised by the young people in the latest study¹. Finally, the need to motivate and engage young people is referenced several times by Carandang et al.¹, reflecting the need for developmentally appropriate interviewing techniques (including motivational interviewing) as core training for all rheumatology professionals, particularly for this age group.

Carandang and colleagues advocate a structured education plan with which the young adults agreed but we would advise some caution here¹. Although structured plans are easier to monitor and measure, adolescent and young adult development is a dynamic process. Young people change biologically, psychologically and/or socially as they grow up, even between clinic visits, so the need to adjust care as the young person grows up needs to be acknowledged. Developmental assessment in rheumatology clinics should be routine as the results of this assessment will determine how to communicate with the young person, how to involve them in decision-making and to assess the effect of the rheumatic condition on the development. This necessary adjustment as the young person grows up is one of the five dimensions within the conceptual framework of developmentally appropriate health care (Box 1)⁵ and is particularly important when considering the effect of relapsing, remitting rheumatic conditions on adolescent and young adult development. A useful resource summarising how developmentally

appropriate rheumatology care for young people can be delivered in the UK was published online earlier this year.

Carandang and colleagues acknowledged some of the limitations of their work, namely the population was primarily white and female and were primarily in the young adult rather than adolescent age range¹. Transitional care should ideally start in early adolescence, but the perspective of a 13 year old in 2022 is very different from that of a 24 year old recalling life as a 13 year old in 2011. Future research in this area should ideally include the perspective of young people in the early and middle stages of adolescent development and not just young adults. Another limitation was that the young people involved were recruited from patient organizations. Young people who are less keen than their peers to join such groups and/or with less voice such as those who do not engage in health care for whom gaps in care are frequent might have had different but equally valuable insights to report. Such young people should not to be forgotten in service developments as they potentially are at risk of worse health outcomes.

One of the strengths of this research was the involvement of young people as both research participants as well as co-researchers. There is increasing awareness of the importance of involving young people in both service development as well as at all stages of research, and not just as research participants⁹.

Another example of such involvement in research is the national youth advisory panel in UK rheumatology, recently described in a study that had two young people as co-authors¹⁰. Meaningful and developmentally appropriate involvement of young people in both research and service developments will ensure that any results or outputs will resonate with their lives. They are, after all, young people first and foremost, learning to live with a long-term health condition. Let us listen to their voices and help ensure their lives are long and rich and fulfilling.

Janet E. McDonagh^{1,2†} and Albert Farre³

¹ Centre for Epidemiology Versus Arthritis, Centre for Musculoskeletal Research, Division of Musculoskeletal and Dermatological Sciences, Faculty of Biology, Medicine and Health, University of Manchester, Manchester Academic Health Science Centre, Manchester, UK.

² National Institute for Health Research Biomedical Research Centre, Manchester University Hospital NHS Trust, Manchester, UK.

³ School of Health Sciences, University of Dundee, Dundee, UK

†e-mail: janet.mcdonagh@manchester.ac.uk

References

1. Carandang, K. et al. Adolescents' and young adults' recommendations for implementing healthcare transition in rheumatology: a mixed methods study. *Arthritis Care Res.* <https://doi.org/10.1002/acr.24977> (2022).
2. Foster, H. E. et al. EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Ann. Rheum. Dis.* **76**, 639–646 (2016).
3. Colver, A. et al. A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC Med.* **16**, 111 (2018).
4. Rettig, P. & Athreya, B. H. Adolescents with chronic disease; transition to adult health care. *Arthritis Care Res.* **4**, 174–180 (1991).
5. Farre, A. et al. Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. *Arch. Dis. Child.* **101**, 628–633 (2016).

6. Boisen, K. A. et al. Is HEADS in our heads? Health risk behavior is not routinely discussed with young people with chronic conditions. *Int. J. Adolesc. Med. Health.* **28**, 429–435 (2016).
7. Kim, B. & White, K. How can health professionals enhance interpersonal communication with adolescents and young adults to improve health care outcomes?: systematic literature review, *Int. J. Adolesc. Youth* **23**, 198–218 (2018).
8. British Society for Rheumatology. *Top tips to ensure provision of developmentally appropriate rheumatology care*
<https://rheumatology.org.uk/Portals/0/Documents/Policy/Developmentally-appropriate-care-top-tips.pdf?ver=2022-06-29-134707-550> (2022).
9. Brady, L-M. (Ed) *Embedding Young People’s Participation in Health services. New approaches.* 1–266 (Bristol University Press, 2020).
10. Esen, E. et al. The Your Rheum story: involvement of young people in rheumatology research. *BMC Rheumatol.* **6**, 43 (2022).

Acknowledgements

J.E.M. is supported by Versus Arthritis Centre for Epidemiology (UK grant No: 21755) and by the National Institutes for Health and Care Research NIHR Manchester Biomedical Research Centre.

Competing interests

J.E.M. has received consultancy fees from CSL-Behring. A.F. declares no competing interests

Box 1: The five dimensions of developmentally appropriate health care

The five dimensions of developmentally appropriate health care for young people⁵:

- Biopsychosocial development and holistic care
- Acknowledgement of young people as a distinct group
- Adjustment of care as the young person develops
- Empowerment of the young person by embedding health education and health promotion
- Interdisciplinary and interorganizational work

Box 1 adapted with permission from ref⁵, BMJ.

