Growing up and moving on in rheumatology: a multicentre cohort of adolescents with juvenile idiopathic arthritis

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Objectives. To define the transitional care workload of a multicentre cohort of adolescents with juvenile idiopathic arthritis (JIA) including disease, self-advocacy and vocational issues prior to the implementation of a transitional care programme. Methods. Data were collected using questionnaires completed by senior clinicians, patients and parents in 10 UK paediatric rheumatology centres. Entry criteria for patients included a confirmed diagnosis of JIA for at least 6 months and an age of 11, 14 or 17 yr.

Results. Of 359 families invited to participate, 308 (85.79%) adolescents with JIA and 303 parents/guardians accepted. Of these, 19.5% had persistent oligoarthritis. Despite their imminent transfer to adult care, ongoing transitional issues were identified in the 17-yr-old cohort: 55.8% were still seeing the rheumatologists with their parent, 20% were not self-medicating, 68.5% had not had intra-articular injections under local anaesthetic and 14% had received no careers counselling. This age group also had significant disease-related issues; 54.6% had moderate to severe functional disability, 67.5% were still on disease-modifying anti-rheumatic drugs and, as a group, they had significantly greater pain than younger patients.

Conclusions. This study has objectively identified the transitional care workload facing paediatric and adult rheumatologists in terms of disease-related, self-advocacy and vocational issues. Outcome data following the implementation of a coordinated transitional care programme are awaited.

Key words: Juvenile idiopathic arthritis, Adolescence, Self-advocacy, Vocational readiness, Transition, Transfer.

In 2000, a national audit reported the under-developed nature of adolescent rheumatology in the UK [1]. Since then, the distinct age and developmental needs of adolescents with chronic illnesses and/or disabilities have been increasingly recognized [2–6]. To meet these needs, transitional care is advocated and should encompass the psychosocial and vocational aspects of care as well as the medical [5, 6]. A needs assessment undertaken with young people with juvenile idiopathic arthritis (JIA), their parents, and a range of professionals in paediatric and adult services [7–10] has set the scene for service development in this area. However, much of the development in transitional care has been in the paediatric sector and, in order to plan appropriate health care for young people with JIA, there remains a need to identify the ‘workload’ and case mix that is being transferred to adult care (in both disease-specific and generic health terms). Accordingly, the aim of this study was to define the adolescent rheumatology ‘workload’ in 10 major UK rheumatology centres prior to the implementation of a transitional care programme for adolescents with JIA. In the context of this study, ‘workload’ refers to the provision of care required to address young people’s (i) JIA and associated morbidities, (ii) developmental care needs and (iii) transitional care needs. ‘Workload’ also encompasses those activities undertaken to meet parental transitional care needs, and thus incorporates the belief that parental support is integral to the transitional care of adolescents with JIA [7–10]. Special reference is made to previously under-reported aspects of care including self-advocacy and vocational issues.

Methods

Participants

Patients and parents were recruited from 10 paediatric rheumatology centres represented in the British Society of Paediatric and Adolescent Rheumatology (BSPAR). Centres were selected to be representative of adolescent rheumatology practice across the UK (i.e. secondary and tertiary centres, rural and urban catchment areas, paediatric and adult rheumatology based units), and to recruit the maximum number of patients. Eligibility criteria for patients included that they (i) had a diagnosis of JIA as defined by the revised ILAR criteria [11], (ii) were expected to remain in the paediatric care of a consultant member of the BSPAR for at least 6 months and (iii) were aged 11, 14 or 17 yr (±1 month). These age-specific entry criteria were selected because they (i) reflect different stages of adolescent development, (ii) facilitate exploration of the importance of timing in transitional care and (iii) avoid discrimination between patients attending the same centre since...
all children in each centre would become eligible for the study when they reached 11, 14 or 17 yr of age.

Procedure

Recruitment was primarily of consecutive out-patients with targeted recruitment employed in smaller centres to optimize final numbers. Clinical data were provided by the senior clinician. Patient and parent data were collected using individual questionnaires designed for self-completion, with support from Local Programme Coordinators (LPCs). All participants gave written informed, assent/consent and the project had Ethics Committee approval.

Outcome measures

Demographic data included age, gender, ethnicity, family structure, the adolescent’s educational status, and the parental marital status, educational qualifications and employment. Socio-economic status was based on the reduced five-class version of the National Statistics-Social Economic Classification (NS-SEC) [12].

Clinical data included JIA onset subtype, age at onset, age at diagnosis, disease duration, duration of care at the centre, secondary diagnoses, current medication, current procedures for joint injections and independent health behaviours (self-medication, independent consultations). These were assessed using a series of closed questions designed specifically for this study (with open questions to gain supplementary data regarding secondary diagnoses).

Core outcome variables included physician’s global assessment of overall disease activity (PGA), erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), active joint count and limited joint count [13]. Adolescents and parents also completed the Childhood Health Assessment Questionnaire (CHAQ), as modified for use in the UK [14] and which also included 100 mm visual analogue scales for pain (VAS-pain) and overall well-being (VAS-global). To enhance completion, an adolescent version of the CHAQ was developed (although currently not validated). This was written in the first person and omitted developmentally inappropriate words (e.g. ‘potty’) and the ‘not applicable’ response. CHAQ scores ranged between 0 and 3 with higher scores indicating greater disability. Following convention [15, 16], all VAS scores were converted into a 0–3 scale with higher scores representing higher levels of pain, disease activity and general health as appropriate. These and the CHAQ scores were subsequently divided into four categories: 0 = none; 0.1–0.5 = mild; 0.6–1.5 = moderate; >1.5 = severe.

Pre-vocational experience was measured in terms of household chores, work experience, career advice received and career aspirations. These were assessed using a mix of open and closed questions developed specifically for this study.

Statistical analyses

The Statistical Package for the Social Sciences (SPSS 9.0) was used to perform all analyses on the quantitative data (Norusis/SPSS, 1993). The Kolmogorov–Smirnov test was used to check for skewness in the distribution of values of each study variable. There was evidence of skewness for some variables, which led to the choice of non-parametric inferential statistics.

Group differences were analysed using Mann-Whitney, Kruskal-Wallis or χ² tests, as appropriate. Associations between the study variables were analysed using Spearman ρ correlations. Statistical significance was set at the 0.01 level to adjust for the multiple tests.

In view of the relatively small numbers of certain JIA subtypes in each age group (Table 1), patients were divided into two main groups; ‘oligoarthritis persistent’ and ‘other’ which were, by definition, primarily polyarticular and/or systemic.

Ethnicity categories were similarly collapsed into ‘White/European’ and ‘other’ which included Pakistani (n = 8), Indian

Table 1. Demographic and disease-related data [all values given as median (min, max) unless stated otherwise]

<table>
<thead>
<tr>
<th>Patient cohort</th>
<th>All, n = 308</th>
<th>11 yr, n = 103</th>
<th>14 yr, n = 128</th>
<th>17 yr, n = 77</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yr)</td>
<td>14.2 (10.9, 18.0)</td>
<td>11.5 (10.9, 12.1)</td>
<td>14.3 (13.9, 15.2)</td>
<td>17.3 (16.8, 18.0)</td>
</tr>
<tr>
<td>Ethnicity: White/European, n (%)</td>
<td>274 (91.0)</td>
<td>97 (94.2)</td>
<td>112 (88.2)</td>
<td>64 (91.4)</td>
</tr>
<tr>
<td>Gender, M:F</td>
<td>1:1.5</td>
<td>1:1.8</td>
<td>1:1.3</td>
<td>1:1.7</td>
</tr>
<tr>
<td>JIA subtype, n (%)</td>
<td>60 (19.5)**</td>
<td>31 (30.1)</td>
<td>23 (18.0)</td>
<td>6 (7.8)</td>
</tr>
<tr>
<td>Oligoarthritis, persistent</td>
<td>248 (80.5)**</td>
<td>72 (69.9)</td>
<td>105 (82.0)</td>
<td>71 (92.2)</td>
</tr>
<tr>
<td>Others</td>
<td>3.5 (0.0, 15.8)**</td>
<td>2.9 (0.0, 10.6)</td>
<td>3.0 (0.0, 14.3)</td>
<td>4.1 (0.3, 15.8)</td>
</tr>
<tr>
<td>Duration of care at current hospital (yr)</td>
<td>9.0 (1.0, 17.0)**</td>
<td>7.8 (1.0, 11.8)</td>
<td>9.5 (1.1, 14.3)</td>
<td>11.4 (1.3, 17.0)</td>
</tr>
<tr>
<td>Age at diagnosis (yr)</td>
<td>5.7 (0.0, 16.3)***</td>
<td>3.9 (1.0, 10.9)</td>
<td>5.8 (0.3, 14.3)</td>
<td>6.9 (0.0, 16.3)</td>
</tr>
<tr>
<td>Disease duration (yr)</td>
<td>10 (0.99)</td>
<td>11 (0.97)</td>
<td>8 (0.99)</td>
<td>10 (0.72)</td>
</tr>
<tr>
<td>Physician Global Assessment (PGA) of disease activity</td>
<td>62 (20.1)</td>
<td>15 (14.6)</td>
<td>30 (23.4)</td>
<td>17 (22.1)</td>
</tr>
<tr>
<td>Cases where disease activity is clinically absent (according to the PGA), n (%)</td>
<td>77 (25.3)</td>
<td>29 (27.3)</td>
<td>38 (29.5)</td>
<td>23 (31.5)</td>
</tr>
<tr>
<td>Active joint count</td>
<td>152 (49.4)</td>
<td>51 (49.5)</td>
<td>65 (50.8)</td>
<td>36 (46.8)</td>
</tr>
<tr>
<td>Cases with no active joints, n (%)</td>
<td>16 (0.100)**</td>
<td>14 (0.99)</td>
<td>15 (1.00)</td>
<td>30 (0.93)</td>
</tr>
<tr>
<td>Adolescent-rated pain score</td>
<td>29 (9.5)</td>
<td>12 (11.8)</td>
<td>10 (8.0)</td>
<td>7 (9.1)</td>
</tr>
<tr>
<td>Cases with no pain, n (%)</td>
<td>55 (18.1)</td>
<td>20 (19.6)</td>
<td>20 (16.0)</td>
<td>15 (19.5)</td>
</tr>
<tr>
<td>Cases with moderate pain, n (%)</td>
<td>69 (22.7)</td>
<td>17 (16.7)</td>
<td>25 (20)</td>
<td>27 (33.1)</td>
</tr>
<tr>
<td>Cases with severe pain, n (%)</td>
<td>2 (0.71)</td>
<td>2 (0.71)</td>
<td>2 (0.52)</td>
<td>2 (0.52)</td>
</tr>
<tr>
<td>Limited joint count</td>
<td>89 (30.1)</td>
<td>27 (27.3)</td>
<td>33 (26.6)</td>
<td>29 (39.7)</td>
</tr>
<tr>
<td>Cases with 5 or more limited joints, n (%)</td>
<td>0.5 (0.0, 3.0)</td>
<td>0.5 (0.0, 3.0)</td>
<td>0.4 (0.0, 2.9)</td>
<td>0.7 (0.0, 2.6)</td>
</tr>
<tr>
<td>CHAQ adolescent rating</td>
<td>66 (21.6)</td>
<td>16 (15.7)</td>
<td>35 (27.6)</td>
<td>15 (19.5)</td>
</tr>
<tr>
<td>No functional disability</td>
<td>94 (30.7)</td>
<td>36 (35.3)</td>
<td>38 (29.9)</td>
<td>20 (26)</td>
</tr>
<tr>
<td>Mild</td>
<td>100 (32.7)</td>
<td>29 (28.4)</td>
<td>42 (33.1)</td>
<td>29 (37.7)</td>
</tr>
<tr>
<td>Moderate</td>
<td>46 (15.0)</td>
<td>21 (20.6)</td>
<td>12 (9.4)</td>
<td>13 (16.9)</td>
</tr>
</tbody>
</table>

Significant differences between age groups: *P < 0.05; **P < 0.01; ***P < 0.0001.
groups in relation to proportions taking DMARDs ($P = 0.096$). Of the 17-yr-olds, 67.5% ($n = 52$) were on DMARDs with 48 of these young people taking more than one type of drug. Only 11.7% ($n = 9$) of this age group were taking no medication at all. There were no differences in the proportions of young people taking more than one type of drug across the age groups ($P = 0.142$). Adolescents on DMARDs had significantly higher physician ratings of disease activity compared with those who were not on DMARDs (respective median PGA scores of 16 (0–97) and 5 (0–97), $P < 0.001$). There were positive correlations between disease activity and adolescent-rated functional disability (i.e. CHAQ) ($\rho = 0.381$, $P < 0.001$). This was also true of parent-rated CHAQ scores ($\rho = 0.418$, $P < 0.001$). Adolescents with persistent oligoarthritis had significantly lower disease activity than those with other JIA subtypes [respective median PGA scores of 5 (0–55) and 10 (0–99), $P = 0.003$].

**Co-morbidities.** With respect to co-morbidities, 49 (15.9%) had surgery, including joint replacements ($n = 10$) and cervical spine surgery ($n = 1$). Forty-five (14.6%) adolescents had osteoporosis, three with proven fractures. Forty-one (13.3%) patients were reported to have had drug toxicity, and where details were given ($n = 38$), almost half (46.7%) were attributed to methotrexate toxicity. There were no significant differences in prevalence of co-morbidities (none vs 1 or more) across the age groups ($P = 0.209$). Nor were there any significant differences between the groups in the proportions that had joint surgery ($P = 0.074$), osteoporosis ($P = 0.502$), growth retardation ($P = 0.172$) or drug toxicity ($P = 0.285$).

**Self-advocacy**

**Independent consultations.** Independent consultations were most likely to be with the rheumatologist or physiotherapist (Table 2). The proportion of adolescents seeing the rheumatologist alone was significantly less than the proportion seeing allied health professionals (when taken as a group) ($P = 0.001$). However, adolescents were more likely to see the rheumatologist independently when compared with their general practitioner ($P < 0.001$). Greater independence was associated with increased age ($P < 0.001$). This said, 15.5% of 17-yr-olds saw no professional alone and 55.8% continued to have parents present in consultations with their rheumatologist. Independence was not associated with any other demographic factor, although there was a trend towards increased independence in males (47.5%, $n = 58$) compared with females (37.8%, $n = 68$) ($P = 0.060$).

**Self-medicating.** Of the 308 patients, 98 (65%) were self-medicating (Table 3) and increased with older age ($P < 0.0001$). However, there were nine 17-yr-olds who were not self-medicating despite median disease duration of 6.0 yr (3.9–11.0 yr), which was not significantly different from those self-medicating ($P = 0.303$).

There was no difference in disease duration between those adolescents self-medicating and those who were not ($P = 0.995$).
Self-medication was positively linked to independent visits for whole group ($P = 0.002$), but largely disappeared when controlled for age.

Joint injections were reported for 208/275 (75.6%) patients (Table 4). In all groups, joint injections were most commonly done under general anaesthetic (GA). This significantly decreased ($P = 0.001$) with older age as joint injections under local anaesthetic increased. However, even at 17 yr of age, less than a third had joint injections under local anaesthetic as occurs in adult practice. There were no significant differences either as a whole group ($P = 0.660$) or within age groups for joint injection practices ($P = 0.721$, $P = 1.000$, $P = 0.364$).

The 17-yr-olds who were having joint injections under local anaesthetic were significantly older at diagnosis than those having GA, Entonox or midazolam (median ages of 12 and 11 yr respectively, $P = 0.017$) and had a shorter median disease duration (6 and 7 yr, respectively $P = 0.034$). There were no differences in core outcome variables including CHAQ and independent visits.

**Vocational readiness.** Most patients were in mainstream education (Table 5). However, 7% of 11-yr-olds and 4% of 14-yr-olds received their education in special needs units or at home. Of these, a third had systemic JIA ($n = 16$, 33.3%) and were more likely to have co-morbidities associated with their JIA ($n = 36$, 87.9%) ($P = 0.000$). In terms of pre-vocational readiness, approximately three-quarters of patients were employed in household activities, with more females involved than males (82.1 vs 69.9%, respectively). There were no differences with respect to age ($P = 0.140$), functional disability ($P = 0.227$) and JIA subtype ($P = 0.459$). Whilst the majority of 17-yr-olds had received work experience and careers counselling, the number of episodes undertaken was typically low. Approximately half of 11- and 14-yr-olds had received no work experience or careers counselling.

**Discussion**

This is the first study to objectively identify the transitional care workload facing paediatric and adult specialists in any chronic illness. Although the data presented are from a UK perspective, many of the issues highlighted are generic to transition, irrespective of health-care system, and provide a useful framework for future research in this area.

**Workload for adult rheumatology care**

The 17-yr-olds in this study provide a good indication of the current workload for adult services, in that they are soon to be transferred (in a UK context), and provide a useful comparison group with the 11- and 14-yr-olds in evaluating the potential benefits of the transitional care programme. It was evident that many 17-yr-olds and parents still had unmet transitional issues which, if left unchecked, are likely to require attention within adult care. Much of the research and development in transitional care has been within the paediatric sector and there is now a need to develop this further in the adult sector. Minden et al. [21] have recently reported the considerable burden and costs of JIA during late adolescence and young adulthood, and further economic evaluation of transitional care will be of interest.

The nature of the disease is an important determinant of the workload for adult rheumatologists. Ideally transition is best when the condition is stable and/or inactive and yet over three-quarters of the 17-yr-olds had persisting disease activity. This is much higher than data from adult studies [19, 22, 23]. Oen et al. [17] reported that the probability of continued active disease into the late twenties or early thirties was high for patients who were not in remission by age 16 yr. Follow-up of this cohort of patients will be of interest as they potentially have benefited from more effective and earlier therapies than previous studies.

Independent visits during transition may be a determinant of successful transfer to adult care [24]. Young people themselves value the choice to be seen independently [8, 25, 26], but may not always feel able to ask their parents and/or professionals for the opportunity to do so [8]. The finding that adolescents tend to see allied health professionals (AHPs) alone more often than the doctor (Table 2) is interesting. Different professional styles of communication and attitudes towards adolescents [26] are possible explanations and worthy of further research particularly with respect to training needs.

Despite the role of primary care professionals being advocated as a key in transition [2], only 27.6% of the 17-yr-olds were...
seeing their GP independently of their parents, significantly lower than that reported in their ‘healthy peers’ [27]. Such practices may influence future health-care utilization in that young people with JIA may not know how to access certain services, skills considered integral to transitional care [28]. Worryingly, an audit conducted prior to this study [29] found little evidence to suggest that the future independent utilization of health services is addressed with patients who have JIA.

Of practical concern, two-thirds of 17-yr-olds requiring intra-articular injections had not yet received them under local anaesthetic, as is the practice in adult care. This can be difficult for young people to contemplate if they have always had injections unconscious. In the authors’ experiences, this is one reason for unsuccessful transfer to adult care and it is suggested, therefore, that the first conscious experience of this procedure should be ideally performed by familiar staff in a familiar place.

The significant morbidity in the 17-yr-olds in terms of disease activity, functional disability and pain should be considered in the context of other transitions that occur concomitantly as they move to adult health care (e.g. school to work/further education, home to independent living). Moreover, Packham et al. [18] have reported that of the 21.1% of adults with JIA reporting previous depression, the first episode typically occurred between 15 and 25 yr of age. It remains unclear whether such young people receive age and developmentally appropriate care within the adult sector, acknowledging that adolescent development itself may be delayed into the adult age range [30]. The unmet education and training needs in adolescent health reported to date would suggest the contrary [3, 9], and training in adolescent rheumatology should be developed by both paediatric and adult rheumatology communities.

Several studies of adults with JIA have demonstrated a risk for unemployment, despite at least average educational achievement [17, 19, 20, 31, 32] and which is not necessarily related to functional disability [19, 20, 32]. Quality of life as an adult with JIA has been shown to be better when employed [19]. Vocational issues were identified as important in the earlier needs assessment [7, 8] and are integral to adolescent rheumatology. The prevalence of pre-vocational skills reported here are reassuring and in part reflects the increased emphasis on careers in the national curriculum. It remains concerning, however, that the median number of careers counselling sessions reported was 1, and 14% of 17-yr-olds had received no careers counselling. However, the vocational data must be interpreted with caution. A single work experience or a single careers counselling session may, or may not, have been useful, appropriate or worthwhile. Similarly, comparative data for ‘healthy’ adolescents are not available. However, Bateman and Finlay [33] recently reported the need for training of health professionals in vocational aspects of chronic illness. Availability of vocational advice specifically for young people within the adult sector is of particular interest. The Swedish experience would suggest this may be suboptimal, with 62% of young adults with arthritis starting in early adulthood reporting no ‘careers discussion with anybody’ compared with 19% of those with childhood-onset arthritis [34]. The impact of the implementation of the Connexions strategy into England and Wales (www.connexions.gov.uk) for young people aged 13–19 (and up to 25 yr if special needs) since the commencement of this study will be of interest, particularly within adult units caring for adolescents with JIA.

Involvement in household chores can be considered as early work experience and has been identified as a marker of resilience for young people with chronic illnesses and/or disabilities [35]. This study reassuringly reported that approximately three-quarters of adolescents were reporting involvement, although there were significantly fewer males than females and data were limited to self-report. It remains unclear whether this is related to cultural or disease-related influences.

JIA during adolescence

The frequency of JIA subtypes in the study is representative of what one would expect in the target population [36], acknowledging that persistent oligoarthritis is characteristically a disease of early/mid childhood, and enthesis-related JIA a disease of late childhood and adolescence. It is debatable that transitional care for persistent oligoarthritis is necessary, although the lower prevalence of independent behaviour may suggest otherwise. Peterson et al. [31] reported a case-control study of young adults with JIA (73% of whom had oligoarthritis), and although the majority perceived their arthritis as mild, patients had lower generic health status than controls [31]. The generic skills of self-advocacy and health-care utilization are also important for all adolescents whether they have a chronic illness, like JIA, or not.

Over a third of adolescents had an adolescent onset of disease. This is a potential challenge to developing transitional care services if the upper age criteria for paediatric units fall below 16 yr, especially if one acknowledges the time required for some young people to adjust to their condition, in addition to preparing to move to a different service. Packham et al. [18] reported that patients developing JIA over the age of 12 yr had the highest risk of developing anxiety-related problems (41.5%). In an earlier study, David et al. [37] reported a trend toward higher scores in ‘anxious preoccupation’ and ‘helplessness’ (which correlates with depression) in individuals with adolescent onset (12–16 yr).

Despite attending specialist centres, pain control was suboptimal, with 90% of adolescents reporting pain. This is similar to reports in both paediatric populations and young adult populations with JIA [18, 38]. Forty per cent of adolescents reported moderate or severe pain with the greatest scores being reported by the 17-yr-olds. This is greater than reported in general paediatric populations with JIA [39, 40] and closer to that reported in studies of adults with JIA [18]. The impact of pain on adolescent development, and conversely how adolescent development affects perception and/or expression of pain, are important considerations in the assessment of an adolescent with JIA. As the choice of anti-inflammatory and/or disease-modifying therapies increases, we must not forget that disease activity does not strongly relate to pain [41]. The importance of age- and developmentally appropriate pain management (including coping strategies and self-management skills) is integral to all adolescent rheumatology services.

When interpreting these data, a number of limitations should be acknowledged. The data must be considered in the context of previous work of the authors [1, 7–10] which preceded patient recruitment and which may have influenced the level of awareness and practice in participating centres. The persisting ‘workload’, however, is evidence for the challenge of translating research evidence and/or policy into clinical practice.

The participating centres were selected to be representative of adolescent rheumatology practice in the UK. However, this means that the variation in policy and practice between these centres requires consideration when interpreting the data. Finally there may be global and cultural differences that have not been identified by this study. The general principles of transition, however, are likely to remain true wherever in the world the young person grows up [2–6, 43].

In conclusion, this study has provided a picture of adolescent rheumatology in the UK at the beginning of the 21st century and agrees with previous studies that state that JIA is not a benign disease in adulthood. This study has also identified previously under-reported important areas of transitional care that need to be addressed in an age- and developmentally appropriate manner prior to transfer to adult care where such expertise [9] and available time [42] may not be readily available. Outcome data following the implementation of a coordinated transitional care programme are awaited with interest.
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J.E.M. is an Arthritis Research Campaign Clinical Senior Lecturer in Paediatric Rheumatology. She co-conceived the study, wrote the grant application, obtained funding, directed the project, co-designed the questionnaire, co-wrote the paper and acted as clinical lead in one participating centre. K.L.S. co-ordinated the project, co-designed the questionnaires, performed the data analyses and co-wrote the paper. T.R.S. co-conceived the study, supervised the grant application and reviewed the paper prior to submission.

The authors have declared no conflicts of interest.

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