Reshaping policy to deliver holistic care for adolescents with Crohn’s disease


Abstract

The number of adolescents with Crohn’s disease (CD) is rising, with one third of cases diagnosed before turning 21 years old. Evidence shows that long-term medical intervention, school absence and the physical toll of CD on the growing adolescent also have a psychological effect on patients. In addition, poorly defined transition pathways are extending these problems into adulthood. The National Institute for Health and Care Excellence (NICE) guidelines are important in shaping service delivery and distribution. However, analysis of the full 2012 NICE CD management guidelines indicates they fall short of providing adequate recommendations for holistic management of the disease in young populations. An update in 2016 added a new clinical recommendation to the guidelines, but no further exploration of the psychosocial aspects of the impact of the disease. The authors of this article used a critical review of literature and concluded that service provision for adolescents with CD could be made better by improving CD support networks, involving young people in the development of policy centred on their care, as well as incorporating other (non-NICE) well-researched CD guidelines in national policy. These changes would improve quality of life for this vulnerable population.

Keywords

adolescence, child health, Crohn’s disease, inflammatory bowel disease, paediatrics, transition

LIVING WITH a chronic illness can have a significant effect on normal adolescent functioning. The stress and after-effects of surgery, the potential discomfort of adapting to a stoma and the uncertainty of how the disease may progress, mixed with the physical toll these processes take on the growing body, bring psychological challenges for these vulnerable patients. Adolescents with Crohn’s disease (CD) can miss months of school due to illness and, in some cases, they may present with signs of low moods, feelings of isolation and can show limited engagement with family and/or healthcare staff.

The long-term nature of the disease means that child and adolescent mental health services (CAMHS) could play an important role, but demands on these services present challenges. The need to improve CAMHS provision is widely recognised, including for children and young people (CYP) whose presenting condition is a mental health problem. Furthermore, mental health is ordinarily seen as secondary to the physical effects of disease, rather than as integral to the whole picture of patient care. It is not surprising that mental healthcare needs may be overlooked in patients with a chronic physical illness. In addition, the large gap between child and adult services results in ill-defined transition pathways, leading to little multidisciplinary focus on this important aspect of adolescent healthcare provision.

This article presents a critical analysis of the full 2012 National Institute of Health and Care Excellence (NICE) guideline ‘Crohn’s Disease: Management in Adults, Children and Young People’, as well as a review of the extensive literature looking at the physical and psychological effects of the disease on adolescents. In the course of the review, it quickly became clear that care provision for adolescents with CD is far from holistic, particularly in terms of addressing the mental health effects of the disease. With government focus recently shifting to the long-overlooked relationship between physical and mental health, the effects of chronic disease on mental health is a topical political issue, and the analysis presented here highlights a number of ways to improve holistic care for this patient group.

Effects on adolescents

CD is a chronic relapsing inflammatory bowel disease (IBD) of unclear aetiology that affects one in 650 people in the United Kingdom (UK) (Steed et al 2011). It is characterised by transmural inflammation, stricture or fistula formation in the gastrointestinal tract...
(Sandhu et al 2010), and can restrict growth, delay puberty, and result in pain, weight loss, diarrhoea, bloody stools and/or anaemia (Sandhu et al 2010, Bishop 2014).

There is no cure for CD: clinical management requires strict, long-term adherence to medication and patients are susceptible to unpredictable relapses. These factors introduce discomfort, embarrassment and uncertainty, with subsequent impact on a young person’s quality of life (QoL) (Bishop 2014).

CD is a disease predominantly diagnosed in youth, with a peak in diagnoses between the ages of 15 and 29 (Hoyde et al 2012). Adolescents, who are defined as being 10-19 years of age (Michaud et al 2007), comprise a significant number of cases. One third of diagnoses are made before the age of 21 and studies indicate that numbers are increasing (Benchimol et al 2011a, Malaty et al 2010).

Adolescence is a period of transition and young people living with CD will face many challenges, which will inevitably affect their QoL. The disease is likely to have significant effects on physical development, puberty, body image, medication adherence, socialisation, education, as well as the eventual transition to adult services (Suris et al 2004, Bishop 2014).

A holistic approach to care for the patient group is therefore vital and, in 2012, guidelines were developed by NICE to forge a national strategy for CD management in the UK. The summarised NICE recommendations have since been updated under the title ‘Crohn’s Disease: Management’ (NICE 2016), adding one further recommendation to the 45 presented in the 2012 full guidelines, totalling 46.

Guidelines

The World Health Organization (2015) defines health policy as ‘decisions, plans, and actions that are undertaken to achieve specific health care goals within a society’. Such policies exist to guide the decisions and actions of healthcare organisations, the establishments directed by these organisations, as well as the professional healthcare workforce. NICE plays a large part in UK healthcare policy as a non-governmental body commissioned by the Department of Health (DH) to produce evidence-based guidelines for disease management. Its guidelines inform clinicians and guide service distribution, with a view to standardising care and removing healthcare inequality (NICE 2013). While there are other CD management policies (Sandhu et al 2010, IBD standards group 2013), these guidelines are more thorough than NICE on some aspects of managing CD, such as on addressing the social consequences of the disease, they lack a CYP population focus, and could also be said to lack the audience of NICE guidelines.

The political context and wide-reaching influence of NICE guidelines marks them out as a primary force for disease management change in the NHS. This gives NICE an elevated platform to influence disease management, so it is vital recommendations are evidence based, up to date and in keeping with modern holistic healthcare delivery (NICE 2013).

The NICE (2012) guideline, ‘Crohn’s Disease: Management in Adults, Children and Young People’ makes 45 recommendations for clinical and non-clinical management of CD, supported by a substantial evidence base. Clinical recommendations include drug therapy for remission and maintenance, enteral nutrition, and surgery as treatment for the disease. These make up the bulk of the recommendations (NICE 2012). The additional 46th recommendation in the 2016 update is a further recommendation for medical management of the disease (NICE 2016).

Non-clinical aspects of the disease are addressed in Section 11, under the heading ‘Patient information and support’, which makes five recommendations (recommendations 39-43) (NICE 2012). The guidance was produced using systematic review methodology to isolate evidence, and a guideline development group consisting of experts (GPs, surgeons, and an IBD specialist nurse), one adult patient and one carer.

Section 11 begins by acknowledging the ‘emotional, psychological, spiritual and social consequences’ of living with CD (NICE 2012). Identified problems include ‘low mood, tiredness, reduced quality of life, effects on family and friends, relationships, education and transition’, all of which have their own relevance in the adolescent population.

The introduction also refers to similar difficulties experienced by parents of children with CD, an important factor when considering adolescents’ needs. However, although the need for holistic, family-centred support appears to be acknowledged in the guidelines, little evidence is used to elaborate the point. In addition, the psychological effects of CD are not further explored, leaving a gap in the guidelines relating to the holistic needs of patients with CD and the psychological repercussions of chronic disease.

This lack of exploration is reflected in the weak evidence base provided to develop and support Section 11’s recommendations. Although NICE places great emphasis on the use of an evidence base to inform and change practice (NICE 2013), the literature search performed to determine the information and support needs of CYP identified no
relevant papers on the topic (NICE 2012). Consequently, the recommendations were based on two subjective papers recommended by a panel member, and the opinion of the GDG (Griffiths et al 1999, Richardson et al 2001).

Both these types of evidence are deemed low quality by the Grading of Recommendations Assessment, Development and Evaluation (GRADE) quality assessment (Jaeschke et al 2008). In addition, these research papers are more than ten years old, which brings into question why more recent publications were not used, when even a quick search of the major databases reveals a number of publications on this subject. No method is described for the literature search, so the approach taken by the authors remains opaque.

Perhaps as a result of this relatively weak evidence the recommendations, although relevant, are vague and undetailed, for example: ‘Give... information on... medicines adherence’ (recommendation 41) or ‘offer... multi-disciplinary support...’ (recommendation 43). The lack of elaboration on these provides clinicians and local authorities with little guidance on what information is to be given, how, when and by whom. It also puts little emphasis on the importance of holistic disease management for wellbeing. Considering the influence of NICE guidelines, this exposes a limitation of the final recommendations. Whereas medical management of CD is thoroughly explored and represented in the recommendations, management of its psychosocial aspects are less well represented, particularly with regards to the adolescent population.

Psychological effects

The association of low mood with CD is not uncommon. Research has found a strong correlation between adolescents with CD and an increased likelihood of presenting with depression, school absences, anxiety and poor social interaction (Nicholas et al 2007, Desmukh et al 2010, Triantafillidis et al 2013). One meta-analysis concluded that, of a number of chronic illnesses considered (including diabetes and tension headaches), IBD had the greatest effect on adolescent mental health (Engstrom 1999). Another meta-analysis of the psychological effects of IBD on paediatric patients highlighted a correlation between IBD, depressive symptoms and internalising disorders (n=1,167) (Greenley et al 2010).

A number of CD-specific factors may contribute to this. For example, the nutritional challenges posed by the disease during the physically demanding period of adolescent growth have been shown to cause pubertal delay and poor growth (Walters and Griffiths 2009). These issues, in turn, have been linked to low self-esteem and depression (Pinquart 2013). The presence of scars and stomas can also affect self-image and sexual relationships, both of which play an important part in social maturation (Muller et al 2009). In addition, the distancing nature of hospitalisation and trauma of surgery is linked to increased social withdrawal and depression (Ananthakrishnan 2013). Another possible contributing factor relates to treatment, with studies showing that corticosteroid medications, one line of treatment, may lead to depressive symptoms (Graff et al 2009).

The case for the psychological burden of CD is therefore significant, and research highlights the effects that this can have on adolescent QoL. Studies show that rates of school absence in patients with CD extend beyond treatment-related reasons, having implications for intellectual maturation and future employment (Mackner et al 2012). In addition, withdrawal, reduced autonomy and overdependence on parents are shown to affect social maturation and individuation – all important aspects of adolescent development (Hysing et al 2009). Parents of young patients with CD can also experience high levels of stress and anxiety related to caring for a child with CD (Mackner and Crandall 2007).

Importantly, recent studies have found links between psychological problems in patients with CD and disease exacerbation, so maintaining mental health may have reciprocal implications for physical health (Ananthakrishnan 2014). The fact that the 2012 guidelines do not adequately account for these widely researched psychological issues means clinicians, local authorities and, on a larger scale, clinical commissioning groups, may not see the importance of recommending and supporting holistic services. This could lead to mental health issues being overlooked in wider policy.

Mental health

In the past, mental health has been neglected in the wider picture of overall health. Historical misunderstanding of psychological disorders has led to ignorance, poor management and stigmatisation (Link and Phelan 2014). However, research and improved understanding have pushed holistic, integrated healthcare delivery to the fore in healthcare politics, emphasising the importance of mental health to overall wellbeing.

This was reflected in the actions of the 2010-2015 coalition government, which pledged to spread political focus to social as well as medical care. As a result, £400million was invested in mental health services reform, leading to
Poor transition has been linked to reduced adherence to medication and low rates of clinic attendance (Leung et al 2011). Contributing to the issue of poorly defined transition pathways is the fact that the changeover between services for young people with CD is poorly addressed in the full 2012 NICE guidelines and the 2016 NICE recommendation update. In the introductory section, readers are referred to the DH framework for transition (Jordan and McDonagh 2006). It is thorough, evidence-based and offers good all-round advice for facilitating transition. However, it does not discuss the specific barriers in transition observed in IBD services. In addition, there is no up to date universal model of transition because the DH transition framework has been archived and new NICE guidelines are yet to be introduced.

Well-managed transition

Another integral aspect of healthcare delivery for adolescents with CD is transition to adult services. The adolescent period has been described as a ‘transition from short-term thinking to long-term thinking’ (Bishop 2014), which is particularly true for young people with chronic diseases, who are learning to understand and manage their disease (Suris et al 2004). A good transition process is key to nurturing this autonomy. Studies suggest that the move from child to adult IBD services is often managed poorly due to significant differences between children’s and adult services (Goodhand et al 2011, Sebastian et al 2012). Paediatric IBD services are led by multidisciplinary teams in tertiary centres, and involve parental decision-making and limited patient autonomy. Conversely, adult services are consultant-led in local centres, and expect patients to be active partners in managing their disease (Goodhand et al 2011). Adult gastroenterologists are reportedly less familiar with managing the more aggressive CD seen in children and this, mixed with the notoriously intimidating culture change, means paediatric gastroenterologists may be hesitant to transition patients (Benchimol et al 2011b).

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Poor transition has been linked to reduced adherence to medication and low rates of clinic attendance. Barker (2003) observed that ‘the biggest sin committed by the NICE guidelines is one of omission’, because, considering their wide-reaching influence, an absence of robust mental health and social considerations may inadvertently contribute to ignorance of the broader social context of disease, resulting in poor disease management.
attendance for IBD patients (Bollegala et al 2013) and, as the 2012 CD guidelines do not explore IBD transition services in depth, there is little effective guidance for those following the guidelines. This gap leaves another important area of adolescent care uncovered, possibly leaving this population vulnerable and unsupported at this pivotal stage of their development.

**Recommendations**

**Converting evidence into action**

CD can have a significant effect on normal adolescent functioning. As already outlined, there is also a growing database of evidence that links CD and mental health issues. This, on top of increasing evidence that many young people with CD will experience a range of problems related to maturation and have a reduced QoL, points strongly to the need for 360° holistic healthcare delivery. This could be achieved through comprehensive assessments of the changing individual needs of children with CD throughout their development. Considerations could include universal involvement of IBD specialist nurses and stoma care nurses, as well as the development and integration of clear psychotherapeutic support pathways for all patients. These changes are most likely to be effected through the provision of well-evidenced, holistic, national guidelines disseminated to all service providers and healthcare professionals, potentially modeled on existing guidelines for other, more common, long-term health conditions such as diabetes.

Aside from the NICE guidelines, there are other well-researched CD management guidelines (IBD Standards Group 2013, Sandhu et al 2010). These contain recommendations for holistic healthcare provision for young CD patients and suggestions on how to optimise IBD service organisation. For example, the Sandhu et al (2010) guidelines include a section with advice on service delivery, which the NICE guidelines do not. However, as with the NICE guidelines, there is limited evidence on the psychological effects of CD on young patients. The IBD standards group (2013) also has a limited evidence-based focus on the psychological effects of IBD, but includes good suggestions for specialist nurse involvement, with a focus on patient-centred care.

These alternative guidelines are not as widely disseminated as the NICE guidelines and so are likely to have a more limited effect on service delivery. There is consequently a strong case for recommendations from other relevant guidelines to be incorporated in the NICE guidelines to ensure they reach a wider audience.

**Developing support networks**

There is evidence of the psychological toll of social isolation, in particular school absences, related to continuing care needs. The development of defined support networks could be one way to tackle the isolation that adolescents with CD may experience. Encouraging peer support and the appropriate use of social media to reach out to this group can help reduce the isolation some may feel when hospitalised, as well as modernising service delivery.

Improving education for teachers and the wider community, by the school nurse network, could help reduce the stigma surrounding CD. This may reduce the embarrassment some young people feel about some aspects of the disease, such as the need for frequent toilet visits or adapting to life with a stoma. Empowering young people in this way would improve services, while enabling adolescents to take control of their own care, in line with effective transition pathways.

**Young people and policy**

Another issue facing the adolescent population is the possible overshadowing of their individual needs by the needs of other child and adult patient groups. With a growing number of young people being diagnosed with CD, it is important young people become independent and active participants in the development of policies that affect them. CYP have been shown to value their own involvement in healthcare decisions (Weil et al 2015), which aligns with the UN Convention on the Rights of the Child (UNCRC) (UN 1989) in encouraging CYP to have freedom of expression and involvement in decisions that affect their lives.

No adolescents were involved in developing the NICE guidelines on CD and there is little research to indicate how and if adolescents are involved in policy development. Recently, patient-centred care has been at the centre of nursing practice, and involving more adolescents in developing policy that affects them would be in keeping with this. In the 25 years since the UNCRC was first defined, many steps have been taken to raise the voice of CYP in health care, including the introduction of the 2014 NHS youth forum and the inclusion of CYP in the NHS Friends and Family test (Wiel et al 2015).

In addition, there is an increasing emphasis on audit and the use of new adolescent-specific QoL assessment tools, such as the IBD knowledge inventory device (IBD-KID), which could involve adolescents in an effective feedback process for policy and guideline development (Haaland et al 2014). This suggests that actions are being taken to improve care provision for the adolescent patient group and
could mean a better future for young people with CD.

Conclusion
Recent political emphasis on improving mental health services and encouraging holistic care means that policy development now takes account of the challenges faced by adolescents with CD. With NICE guidelines encompassing social care as well as clinical care, holistic models of care may soon be integrated in the already-existing national guidance for complex conditions such as CD.

Until then, the political voice of adolescents is at risk of getting lost between children’s and adult services. Involving CYP in the management of their care by listening to them on an individual, local and national levels will enable holistic care provision to be comprehensively secured for them.

References


