

The Transitioning From Pediatric to Adult Inflammatory Bowel Disease Services: A Qualitative Study of Adolescents and Their Parents

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Abstract

Background: Inflammatory bowel disease (IBD) often has its onset during late childhood and adolescence, a time of significant change. Young people may be required to transition from a pediatric to an adult IBD service during this time. The transition from pediatric to adult services can be a high-risk period for poor outcomes for emerging adults with IBD. We seek to understand the concerns of patients and carers during this period.

Methods: Semi-structured interview and interpretative phenomenological analysis were used to explore the experiences of 16 young persons and 10 of their parents during transition.

Results: The narrative analysis reflected the importance of three aspects of transition to the young people and their parents during transition. The process of adjusting to illness, parents letting go, and the young person “growing up” were key themes.

Conclusion: In addition to patient needs, parental grief and adjustment may be easily overlooked in the transition period: children who only recently needed intensive parental care and involvement may now be seeking higher degrees of autonomy. These findings indicate a role for including psychological interventions addressing

the well-being of parents in transition programs.

Keywords: Adolescent health; Inflammatory bowel disease; Transition

Introduction

The onset of inflammatory bowel disease (IBD) is often during early adolescence, a time of significant change. During this period, the young person is also required to transition from pediatric to adult IBD services, becoming increasingly responsible for their own health management. At the same time, adolescents are often also starting to take steps towards independence from their parents. The families and parents of young people with IBD also suffer destabilization and stress as a result.

The transitioning from pediatric to adult health services can present a new challenge for emerging adults and their families. Adult services, with their focus on the individual patient and advocacy of patient independence, present a marked contrast with the multi-disciplinary, family-focused approach that characterizes pediatric services. A poorly managed transition process can result in significant adverse outcomes, including treatment non-adherence, increased disease severity, and undue financial and emotional stress for patients and families [1]. As a result of these concerns, current international guidelines have made recommendations for structured transitioning programs which are “uninterrupted, coordinated and matched to the developmental abilities of the individual” [2].

The development of such a program would require an appreciation for the perspectives and concerns of the key stakeholders in the transitioning process: the young people themselves, their families, and the pediatric and adult providers. The research exploring these perspectives has generally employed survey-based (quantitative) methodologies [3, 4], or, increasingly, qualitative [1, 5] or mixed [6] methodologies. There is little research addressing the specific concerns and perspectives of parents, unless as part of broader studies exploring perspectives of multiple stakeholders, and the research to date has tended to rely on focus group data rather than individual interviews [1].

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Aims

We established a transitional IBD clinic with a dedicated adolescent interested adult gastroenterologist, and support staff. We wanted to explore the experiences of patients who transitioned directly from the pediatric to the adult service before the transitional clinic was established, as well as those who engaged in the new transitional clinic. We also wanted to explore the experiences of parents and carers.

Materials and Methods

The research was approved by the ACT Health Human Research Ethics Committee (Protocol ETH.4.17.085). The study was conducted in compliance with the ethical standards of the responsible institution on human subjects as well as with the Helsinki Declaration. Participants were invited to participate in the research by the specialist gastroenterologist attending a transitional IBD clinic in a tertiary hospital. We used semi-structured interviews and interpretative phenomenological analysis (IPA) to explore the experiences of four parents of young adults with IBD. IPA is a qualitative analytic approach which has become increasingly popular, particularly in areas of health psychology [7]. The core features of IPA have been described as “idiographic analysis balancing experiential claims against more overtly interpretative analyses; drawing from small samples; and focusing on verbatim accounts” [8].

We conducted semi-structured interviews, which were audiotaped, with patients receiving care from the Gastroenterology and Hepatology service at Canberra Hospital, along with their parents. Qualitative thematic interview analysis was undertaken separately by two clinicians who then met to agree on key themes. Data were collected using taped, semi-structured, face-to-face in-depth interviews. Semi-structured interviews are considered to be the ideal method of data collection for IPA studies as they permit detailed discussion of particular concerns and probing of important individual topics which arise [7]. The interviewers were informed by a schedule of questions prepared beforehand and covered the participants’ memories of their children’s initial diagnosis, their relationships with the pediatric and adult treating teams and their impression of their children’s transition to adulthood generally. Verbatim transcripts of the semi-structured interviews served as the raw data for the analysis.

Following familiarization with the content of the transcripts through listening to the audio recordings and reading and re-reading the transcripts, researchers met to discuss the initial impressions of the data, as well as the independently conducted thematic analysis of the young peoples’ interviews. The decision was made for one of the authors to proceed with detailed analysis of the parents’ interview transcripts. The data analysis followed the four-stage process described in detail by Smith and Shinebourne [9]. The author made a close interpretative reading of each interview transcript, annotating the experiential claims, concerns and understandings of each participant. The initial readings were translated into emergent patterns emphasizing convergence and divergence,

commonality and nuance within the individual accounts, and then subsequently across the participants’ accounts. A table of superordinate and subordinate themes with supporting quotations was created. After analysis was conducted on each case, patterns were established cross-case and documented in a master table of themes for the group. Another author reviewed and audited the themes to ensure that they were grounded and well represented in the transcripts. The master table was then transformed into a narrative account; the analytic account is supported by verbatim extracts from each participant.

Patients also completed the IBD Questionnaire (IBDQ), the Kessler Psychological Distress Scale (K10), the Patient Doctor Relationship Questionnaire (PDRQ-9), and the Stressful Life Events Questionnaire. Clinical details were obtained from the hospital file.

Twenty young people were considered to be eligible for the project according to the recruitment criteria. Two young people declined to participate, and two contributed to the quantitative component of the research but were not available to take part in the interviews. Out of the 16 young people who were interviewed, 12 consented for their parents to be interviewed. Eight parents were available and ultimately interviewed. Three parents were interviewed jointly with their children. Another parent was the mother of three participants in the study.

Results

Sixteen IBD patients (nine male, seven female) between the ages of 15 years 11 months and 20 years 11 months were recruited from a transitional adolescent IBD service. Participants were residents of the local catchment area of the participating institution. The average age of participants was 17. Structured interviews were conducted with each of these patients, along with 10 of their carers.

The transitional clinic had a higher proportion of participants with Crohn’s disease. In the non-transitional group there were more males, and the reverse in the transitional group. The non-transitional clinic patients had more active disease, use of steroids, and emergency department presentations. The mean C-reactive protein (CRP) of 36 mg/L at the first visit to the non-transitional clinic improved to 12 mg/L at last follow-up, whereas mean CRP at first and last visit to the transitional clinic remained at 2 mg/L. There were similar rates of attendance in both clinics.

In the transitional and non-transitional clinics respectively, the mean IBDQ was 193 (standard deviation (SD) = 31) and 174 (SD = 22) with higher scores reflecting better health-related quality of life. The K10 mean score was 16 (SD = 7.5) and 17.5 (SD = 4.3) indicating a moderate level of distress. The PDRQ-9 mean scores were 4.3/5 (SD = 0.75) and 4.8/5 (SD = 0.4) indicating good therapeutic relationships, and both groups reported a similar number of stressful life events in the last year.

The thematic analysis of the patients and carers responses revealed that adjustment to illness, relationship with parents and the transitioning to adulthood were three main areas of concern to patients during transitioning.

Table 1. Themes Emerging From Interviews With Adolescents and Their Parents

Adjustment to illness	<p>“I was very sick, it was painful and I didn’t know what it was. I thought it was something really bad, I was scared, I didn’t know what it meant, had never heard of it ... I didn’t know what this disease meant for my life ... I was embarrassed ... I couldn’t talk about it openly.” (Female, 19)</p> <p>“Yeah. It was a shock. Yeah. Yeah. You question: Why has it happened? How has it happened? ... I’ll take all the pain ... let him be pain free.” (Father)</p>
Relationship with parents	<p>“When I was 16 I made some close relationships with the nurses, because they got to know me quite well after seeing me for long periods, and I found that they really got me through those days in the hospital when my parents weren’t there, they sort of made up for that.” (Female, 19)</p> <p>“You know. We’ve had ... we’ve had big talks ... me and you have been through ... more things than most dad/daughter would ever go through ... I didn’t know what was going to happen to my daughter. I mean ... they came speaking with me and my wife when ... I thought she was going to die.” (Father)</p>
Transitioning to adulthood	<p>“It’s also I think me becoming more independent ... It has ... has helped [my parents] as well ... because it ... it gets them not to focus on me so much, but they can focus on themselves and their own lives, and ... their own ... whatever problems they might have.” (Male, 20)</p> <p>“These guys are all really friendly ... like ... but they’re ... not as like ... the nurses at pediatrics, who like ... talked to you for ages and ages. They are not as busy over there ... These guys sort of are just like ... get the job done and like ... move on.” (Female, 20)</p> <p>“[The doctor] was ... incredibly warm and ... and... reassuring and was always available to ... explain things ...” (Mother)</p> <p>“I’ve had to be a lot more independent and learn how to do things myself, and I’ve sort of stepped back into be an adult, I didn’t have to do that as much when my mum was around ... it makes me feel pretty good to be able to do all of this at the age of 19.” (Female, 19)</p> <p>“I was a bit sad to see [my doctor] go because he’d helped me out so much ... and if he ever wanted to know I could easily update him on how it was, but it was quite a sad separation because I’d spent so much time seeing him and he’d helped me a lot.” (Female, 19)</p> <p>“In my teen years ... um ... and I guess ... yeah, when something, you know ... gets me a bit down, like you know ... my Crohn’s or ... you know ...it starts flaring up, [my mother] gets a bit worried.” (Male, 20)</p> <p>“I’ve finished high school and now I’m working. I really love it. I still live at home. I live with my mother father and brother. I’d like to move out and planning to do that soon. I’m a very private person, my mum is my best support, she comes with me to appointments still, even though I can do it myself it’s nice to have her there, she knows what the medications are.” (Female, 19)</p>

Discussion

Adjustment to illness

The nature of the symptoms patients experience along with the difficulties with and uncertainty around diagnosis, were all reported to have impacted the young person’s mood, confidence, daily life and self-concept. For some, the fear of the unknown, the fluctuating nature of the symptoms, and difficulties sharing with others due to shame associated with the nature of the symptoms led to intense feelings of loneliness and increasing reliance on close family members, and for parents/carers a similar experience, as shown in Table 1.

Relationship with parents

The relationship with parents was also a central to how the young patients coped with transition. When describing times of hospitalization young people recognized the important ruptures and shifting reliance on medical teams and the implica-

tions this had for their transition. The young person’s relationships with their medical team and their parents were both seen as important to transition. Importantly, the closeness they felt with their pediatric team led to some difficulties separating, while others clearly recognized the reliance on parents when they were sick made it harder to “let go”.

One parent reported the fear of their child dying had led to increased closeness between them and their child. The implication of the nature of the relationship was therefore even more important in the transitioning process. For example, the relationship between the young person and their parent, the willingness of parents to “let go” may have hampered their steps towards independence during transition.

Transitioning to adulthood

Finally, the transitioning to adulthood was recognized as a key aspect of transitioning and the young person could feel both responsibility and trepidation in taking those steps towards independence. When parents felt reassured through the transitioning process this can clearly benefit the young person’s

confidence around self-management and “growing-up”. This represents an important goal in the transitioning process.

Receiving care from one’s parent may create a responsibility for the burden placed on the parent, which the young person is required to manage. At the same time young people can gain reassurance that their parent’s care will continue and changing as they require. Managing the fears and needs of both the young person and the parent through the transitioning is therefore required to be managed in an individualized way, with the young person increasingly being encouraged to make the decisions.

Implications and contributions

Adolescents who are the same age may be at very different stages of autonomy and individuation. The transition period may be a particularly difficult time for parents, who have been extremely protective of their very sick children, and now have to relinquish some responsibility and contact with clinicians as their children develop increased autonomy. Qualitative investigations of parental concerns and experiences can provide valuable information for healthcare providers to consider in developing transition programs for young people with chronic diseases including IBD.

Our findings identify the priorities of clinicians supporting the adolescents during transition. It also supports the existence of a transitional, flexible model of care in-between pediatric and adult services, one in which parents, carers and adolescents can experiment with new roles and autonomy, but with the flexibility to return to the safety of previous family roles and arrangements at times of stress.

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Conflict of Interest

The authors are employees of Canberra Health Services. The authors have no conflict of interest to declare in regards to the publication of this manuscript.

Informed Consent

Informed consent was obtained from all individuals included in this study.

Author Contributions

KS, RP, PH, and PK conceived and designed the study. MB, PH, RP, PK, and KS collected and analyzed data and wrote the manuscript. All authors have accepted responsibility for the entire content of this manuscript and approved its submission.

Data Availability

The data supporting the findings of this study are available from the corresponding author upon reasonable request.

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