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The Longitudinal Relationship Between Satisfaction with Transitional Care and Social and Emotional Quality of Life Among Chronically Ill Adolescents

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Abstract This study aimed to identify the relationship between satisfaction with transitional care and quality of life of chronically ill adolescents over time. This longitudinal study included adolescents with type I diabetes, juvenile idiopathic arthritis (JIA), and neuromuscular disorders (NMD). At baseline 138 respondents (response rate 31 %) filled in a questionnaire and 188 about 1 year later (response rate 43 %). Analysis of variance showed that adolescents with diabetes reported the highest physical quality of life, followed in order by those with NMD and JIA ($p \leq 0.01$). Adolescents with diabetes reported the highest social quality of life, followed in order by those with JIA and NMD (both at $p \leq 0.001$). Univariate analyses showed that satisfaction with transitional care at T0 was significantly related to emotional and physical quality of life at T1 (both at $p \leq 0.05$). At T1, satisfaction with transitional care was significantly related to the emotional, physical, and social domains of quality of life (all at $p \leq 0.001$). Multiple regression analyses revealed that satisfaction with transitional care at T1 was related to emotional ($\beta -0.20$; $p \leq 0.05$) and social ($\beta -0.35$; $p \leq 0.01$) quality of life domains over time. This indicates that lower gap scores, which measured differences between ‘best care’ and ‘current care,’ are associated with better social and emotional quality of life in this sample of adolescents. Satisfaction with transitional care and social and emotional quality of life are related over time.

Keywords Quality of life · Adolescents · Satisfaction with care · Quality of care · Diabetes · Juvenile idiopathic arthritis · Neuromuscular disorders

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Introduction

Advances in medical technology have resulted in considerable improvements in the prognosis of chronic conditions, which has increased the likelihood of chronically ill children reaching stages of adolescence and adulthood (Blum et al. 1993; Scal 2002) and in turn increased numbers of adolescents with a chronic condition (Crowley et al. 2011). This growing number of adolescents with chronic health conditions who survive into adulthood has brought the issue of transition from child to adult care to the attention.

Many adolescents with chronic health conditions experienced difficulties in the transfer to adult care and to adjust to their increased responsibility for their own care when using adult services (Anthony et al. 2009; Dovey-Pearce et al. 2005; O’Connell et al. 2003; van Staa et al. 2011a, b). This transition is a long and complex process, which occurs during an already challenging passage from adolescence to adulthood (Kelly et al. 2002; Lugasi et al. 2011; Rosen 2004). Adolescents with chronic health conditions are expected to become increasingly mature and independent, which implies a role change between parents and adolescents and between adolescents and healthcare professionals (Blum et al. 1993; Rosen 2004). As they gradually grow out of the pediatric care, chronically ill adolescents desire healthcare professionals’ attitudes to become less childish, more age-appropriate, and to be treated as an equal partner in care (van Staa et al. 2011b). Health care professionals should inquire preferences of adolescents with chronic health conditions and adjust their communication style and treatment plans accordingly. In addition, research shows that there is no ‘one size fits all’ approach to adolescent health care. There are individual differences in preferences between adolescents with chronic health conditions (Jedeloo et al. 2010).

Transition between pediatric and adult care for adolescents with chronic health conditions is often poorly managed, with negative consequences on health and quality of life outcomes (Betz 2004; Lotstein et al. 2008; McDonagh 2005; Oeffinger et al. 2005; Reiss et al. 2005; Wojciechowski et al. 2002; Watson 2000; Wysocki et al. 1992; Yeung et al. 2008). As young people mature and their medical and personal needs change, it is important that they receive age-appropriate health-care tailored to their medical and personal needs in order to protect their quality of life (While et al. 2004). Transition programs have been developed to bridge the gap between pediatric to adult care (Blum 1993; Scal 2002; McDonagh 2005; Reiss et al. 2005). Transition of care is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum et al. 1993). Satisfaction with transitional care is thus a necessary component of caring for adolescents with chronic health conditions (Binks et al. 2007; Nakhla et al. 2008; McDonagh et al. 2007). The optimal goal of transitioning from child- to adult-oriented care is to provide adolescents with uninterrupted, coordinated, developmentally appropriate, and comprehensive healthcare that addresses their medical, psychosocial, and educational/vocational needs (McDonagh et al. 2000; Blum et al. 1993). Transitional care services are expected to help smooth the process to avoid gaps in health care and maximize adult quality of life (Lotstein et al. 2009). Transitional care may consist of preparing adolescents for the transfer to adult-oriented care by formulating self-

management goals using an individualized self-management plan or by practicing self management skills by seeing the physician without their parent being present. Also joint consultations in which the paediatrician and medical specialist from adult care together consult with the adolescent in one session may serve to prepare the adolescent for transfer.

The need for transitional care is well established for adolescents with chronic health conditions (Shaw et al. 2005, 2004a, b), but the quality of life outcomes of such care remain unclear. A limited number of studies have evaluated transitional care programs that support beneficial outcomes for patients with various chronic diseases (McDonagh 2005; Nakhla et al. 2008; Rettig and Athreya 1991; Zack et al. 2003), but most of these studies have not investigated the effects of these programs on quality of life. In the only study to date investigating quality of life impacts, McDonagh et al. (2007) found evidence that coordinated transitional care can potentially improve quality of life in adolescents with juvenile idiopathic arthritis. We do not know the longitudinal relationship between transitional care and quality of life among adolescents with other chronic conditions. The medical and healthcare fields face the challenge of assessing the quality of life and experiences of adolescents with chronic health conditions who receive transitional care, with the aim of improving quality of life in this patient population. Thus, the aim of this study was to investigate the relationship between satisfaction with transitional care and quality of life over time among adolescents with various chronic conditions.

Methods

Setting and Design

This longitudinal study was part of a larger evaluation of a collaborative Dutch quality-improvement program called 'On Your Own Feet Ahead!'. This program aimed to develop and implement innovative transitional care interventions for chronically ill adolescents. The "breakthrough method" was used as a model for improvement and implementation. Improvement teams from various organizations joined forces to achieve substantial improvements within a 1-year timeframe. Headed by a project leader, each temporary improvement team generally consisted of four to five providers from pediatric and adult care.

The improvement teams from the participating organizations were invited to attend four national conferences offering workshops and sessions in which questions could be posed to other teams or experts. Program managers provided training and instructions on the improvement methods, transferred knowledge on transitional care and acted as counsellors. The improvement teams developed and implemented their interventions under the guidance of the program managers. A toolkit with transitional care interventions was offered to each team. Examples of transitional care interventions are an individual self management plan, availability of a transition coordinator and transition protocol. Teams were invited to decide on the interventions based on their client type and the local context.

As part of a larger evaluation research, this study surveyed patients treated by teams that delivered care to adolescents with type I diabetes, juvenile idiopathic

arthritis (JIA), and neuromuscular disorders (NMD); the latter were treated with chronic mechanical ventilation.

Participants and Survey Procedure

As part of the program evaluation, adolescents treated by the teams were asked to complete questionnaires. At baseline 138 respondents (out of 441; response rate 31 %) filled in a questionnaire and 188 about 1 year later (out of 433; response rate 43 %). A total of 123 respondents filled in the questionnaire at both T0 and T1. Eligible participants were selected by the participating teams. They were 12–25-year-olds in active long-term pediatric treatment. Two exclusion criteria were applied: already transferred to adult care; and documented diagnosis of intellectual impairment. Approval for the study was obtained from the Erasmus Medical Centre Institutional Review Board. Eligible adolescents received written information and a unique access code, and were invited to complete a web-based questionnaire. Non-respondents received a reminder by mail after 2 weeks, including a printed copy of the questionnaire. There was no financial remuneration, although participants were entered in a lottery with a chance to win an iPod. At follow-up all eligible adolescents (respondents as well as non-respondents at T0) were invited to complete questionnaires. About 2 weeks later a reminder was sent. In addition, after the reminder, non-responders were asked by telephone to complete the questionnaire.

Measures

The structured survey for adolescents asked respondents to provide background characteristics, such as age, gender, and type of chronic condition. Quality of life was assessed with the DISABKIDS condition-generic module questionnaire (Petersen et al. 2005), which consists of 37 items grouped into six dimensions: independence, physical limitation, social inclusion, social exclusion, emotion, and medication. The six dimensions were conceptually associated with three higher-order domains: emotional, physical, and social quality of life. The emotional domain incorporated the positive aspect of independent living (independence dimension), as well as all kinds of emotional reactions to having a chronic condition (emotion dimension). The physical domain included physical symptoms and limitations due to the chronic condition (physical limitation dimension), as well as the impact of taking medicine (in the forms of pills, injections, etc.; medication dimension). The social domain included aspects of stigma (social exclusion dimension) and support from friends, family, and others (social inclusion dimension) (Schmidt et al. 2006). Responses to each item were structured using a five-point Likert scale (1 = never, 2 = seldom, 3 = quite often, 4 = very often, 5 = always). Domain scores were transformed linearly to a 0–100 scale, with 100 indicating the highest quality of life. Cronbach's alpha values of the DISABKIDS condition-generic module social (0.80 at T0, 0.84 at T1), emotional (0.90 at T0, 0.92 at T1), and physical (0.84 at T0, 0.81 at T1) domains all indicated good reliability.

We used the 'Mind the Gap' instrument (Shaw et al. 2007, 2004c), which was developed to assess satisfaction with transitional care among adolescents with chronic health conditions, to assess adolescents' experiences with and expectations of

transitional care. Responses to each of the 22 items of this instrument were structured on a seven-point Likert-scale ranging from 1 (strongly disagree) to 7 (strongly agree). The items included statements about issues identified as important in earlier needs assessments (Shaw et al. 2004a, b), including management of the environment (five items), provider characteristics (11 items), and process issues (six items). Gap scores were calculated as the differences between 'best care' and 'current care' as perceived by the adolescents with no difference (score = 0) indicating the absence of a discrepancy. A positive gap score indicated that 'current care' did not meet the standards of the 'expected best care,' and more positive scores indicated lower levels of satisfaction. Cronbach's alpha values confirmed the reliability of the Mind the Gap instrument (0.89 at T0, 0.88 at T1).

Statistical Analyses

We investigated the longitudinal relationship between satisfaction with transitional care (Mind the Gap scores) and the emotional, physical, and social domain scores of the DISABKIDS condition-generic module instrument. Descriptive analysis included the calculation of means and standard deviations. Differences between scores at T1 and T0 were established with two-tailed paired *t*-tests, and quality of life and satisfaction with transitional care were compared among adolescents with different chronic conditions using analysis of variance. Bivariate correlations between satisfaction with care and the quality of life domains were first identified. Multiple regression analyses were then performed (among respondents who filled in questionnaires at both T0 and T1 only) to reveal significant longitudinal relationships between satisfaction with care delivery and quality of life domains after controlling for quality of life at T0, age, gender and type of chronic condition. All statistical analyses were conducted with SPSS software (ver. 17.0; SPSS, Inc., Chicago, IL, USA).

Results

At T1, 58.8 % of respondents were female and their mean age was 17 ± 1.7 (range, 12–20) years. About half (53 %) of the respondents reported having diabetes, 37 % had JIA, and 10% had NMD. The overall mean quality of life at T1, as measured with the DISABKIDS condition-generic module instrument, was 74.9 ± 14.5 .

The emotional, physical and social domains of quality of life did not differ between T0 and T1. Mean gap scores, indicating perceived satisfaction with transitional care, also did not differ between T0 and T1.

Table 1 shows differences between chronic conditions in quality of life domains and satisfaction with transitional care. These results indicate that physical domain scores varied among chronic conditions at T1 ($F_{\text{group}}=5.385$; $p \leq 0.01$), but not at T0 ($F_{\text{group}}=0.836$; $p=0.436$). At T1, adolescents with diabetes reported higher physical quality of life than did those with NMD or JIA. Social domain scores varied among chronic conditions at both T1 ($F_{\text{group}}=9.665$; $p \leq 0.001$) and T0 ($F_{\text{group}}=7.271$; $p \leq 0.001$). Adolescents with diabetes reported the highest social quality of life, followed in order by adolescents with JIA and those with NMD at both T0 and T1. No difference among chronic conditions was observed in emotional domain scores at

Table 1 Differences between chronic condition in quality of life domains and satisfaction with transitional care

| | T0 | | | | | | T1 | | | | | |
|-------------------------------------|------|------|----------|-------|-------|------|------|------|----------|-------|-------|--------|
| | JIA | NMD | Diabetes | Total | F | p | JIA | NMD | Diabetes | Total | F | p |
| Emotional quality of life | | | | | | | | | | | | |
| n | 31 | 12 | 72 | 115 | 0.133 | .873 | 68 | 17 | 95 | 180 | 0.881 | .416 |
| mean | 78.0 | 79.0 | 76.8 | 77.4 | | | 74.8 | 76.7 | 78.2 | 76.8 | | |
| sd | 16.2 | 14.5 | 16.2 | 15.9 | | | 17.6 | 16.1 | 15.2 | 16.1 | | |
| Physical quality of life | | | | | | | | | | | | |
| n | 22 | 12 | 71 | 105 | 0.836 | .436 | 55 | 13 | 94 | 162 | 5.385 | .005 |
| mean | 63.5 | 71.7 | 67.5 | 67.2 | | | 61.8 | 66.3 | 70.9 | 67.5 | | |
| sd | 17.7 | 13.8 | 18.9 | 18.2 | | | 16.9 | 11.5 | 16.6 | 16.8 | | |
| Social quality of life | | | | | | | | | | | | |
| n | 31 | 12 | 72 | 115 | 7.271 | .001 | 68 | 17 | 96 | 181 | 9.665 | ≤ .001 |
| mean | 77.5 | 67.5 | 82.1 | 79.4 | | | 76.0 | 71.2 | 83.9 | 79.8 | | |
| sd | 15.4 | 11.5 | 11.5 | 13.3 | | | 16.6 | 11.2 | 12.7 | 14.9 | | |
| Satisfaction with transitional care | | | | | | | | | | | | |
| n | 30 | 11 | 72 | 113 | 0.481 | .620 | 69 | 16 | 97 | 182 | 0.229 | .742 |
| mean | 0.3 | 0.5 | 0.2 | 0.3 | | | 0.5 | 0.5 | 0.4 | 0.5 | | |
| sd | 0.9 | 1.2 | 1.0 | 1.0 | | | 0.9 | 1.0 | 1.0 | 0.9 | | |

JIA juvenile idiopathic arthritis; *NMD* neuromuscular disorders. A description of the quality of life and satisfaction with transitional care instruments can be found in the measures paragraph in the [Methods](#) section

T1 or T0. Similarly, satisfaction with transitional care did not differ among conditions at T1 or T0.

The results of univariate analyses showed that satisfaction with transitional care at T0 was significantly related to emotional and physical quality of life at T1 (both at $p \leq 0.05$; Table 2). Satisfaction with transitional care at T1 was significantly related to the emotional, physical and social domains of quality of life at T1 (all at $p \leq 0.001$).

Table 3 displays the multiple regression analyses. A strong longitudinal relationship was found between emotional quality of life at T0 and emotional quality of life at T1 ($\beta = 0.69$; $p \leq 0.001$). In addition, after controlling for emotional quality of life at T0, age, gender and chronic condition; we found a significant relationship between satisfaction with transitional care at T1 and emotional quality of life at T1 ($\beta = -0.20$; $p \leq 0.05$). We also found a strong longitudinal relationship between physical quality of life at T0 and physical quality of life at T1 ($\beta = 0.56$; $p \leq 0.001$). Adolescents with diabetes reported significantly higher physical quality of life than did adolescents with JIA ($\beta = 0.27$; $p \leq 0.01$). A strong longitudinal relationship was also found between social quality of life at T0 and social quality of life at T1 ($\beta = 0.58$; $p \leq 0.001$). After controlling for social quality of life at T0, age, gender and chronic condition, satisfaction with transitional care at T1 was significantly associated with social quality of life at T1 ($\beta = -0.35$; $p \leq 0.01$). This indicates that lower gap scores,

Table 2 Associations between satisfaction with transitional care and quality of life in adolescents with chronic health conditions

| | Emotional quality of life at T1 | | Physical quality of life at T1 | | Social quality of life at T1 | |
|-------------------------------------|---------------------------------|-------|--------------------------------|-------|------------------------------|-------|
| Satisfaction with transitional care | | | | | | |
| T0 Gap score | -0.23* | n=81 | -0.25* | n=75 | -0.14 | n=81 |
| T1 Gap score | -0.27*** | n=179 | -0.28*** | n=162 | -0.28*** | n=180 |

*** $p \leq 0.001$; ** $p \leq 0.01$; * $p \leq 0.05$ (two-tailed)

which measured differences between 'best care' and 'current care,' are associated with better social and emotional quality of life in this sample of adolescents.

Discussion

This study evaluated the longitudinal relationship between satisfaction with transitional care and the emotional, physical, and social domains of quality of life among adolescents with diabetes, JIA, and NMD. Adolescents with diabetes had the highest social and physical quality of life outcomes, with JIA reported the lowest physical quality of life outcomes, and those with an NMD reported the lowest social quality of

Table 3 Longitudinal relationship with quality of life as assessed by multiple regression analyses

| | Emotional quality of life at T1 (n=80) | Physical quality of life at T1 (n=72) | Social quality of life at T1 (n=80) |
|-------------------------------------|--|---------------------------------------|-------------------------------------|
| Quality of life at T0 ^a | 0.69*** | 0.56*** | 0.58*** |
| Background characteristics | | | |
| Age | 0.01 | 0.01 | 0.05 |
| Gender (Male) | 0.03 | -0.02 | 0.03 |
| Chronic condition | | | |
| Diabetes | 0.01 | 0.27** | 0.03 |
| Neuromuscular disorder | 0.00 | 0.15 | 0.01 |
| Satisfaction with transitional care | | | |
| T0 Gap score | 0.10 | -0.07 | 0.18 |
| T1 Gap score | -0.20* | -0.10 | -0.35** |
| Adjusted R ² | 51.7 % | 42.7 % | 39.8 % |
| F | 13.252 | 8.664 | 7.306 |

*** $p \leq 0.001$; ** $p \leq 0.01$; * $p \leq 0.05$ (two-tailed). Juvenile rheumatoid arthritis is the reference group of the chronic conditions. Listwise deletion of missing cases was used for the analyses. Findings are based on respondents who filled in the questionnaire at both T0 and T1 only

^a Emotional quality of life at T0 was used as independent variable to assess the longitudinal relationship with emotional quality of life at T1. Physical quality of life at T0 was used as independent variable to assess the longitudinal relationship with physical quality of life at T1. Social quality of life at T0 was used as independent variable to assess the longitudinal relationship with social quality of life at T1

life outcomes. No difference in emotional quality of life was found among adolescents with these chronic conditions. The overall mean quality of life, as measured with the DISABKIDS condition-generic module instrument at T0 (74.4 ± 14.1) and T1 (74.9 ± 14.5), were comparable to the findings of Schmidt et al. (2006), who used the same instrument to measure overall quality of life (76.9 ± 14.8) among adolescents in a variety of countries with various chronic conditions.

Whereas univariate analyses revealed that satisfaction with transitional care was related to all three quality of life domains, multiple regression analyses only demonstrated a significant relationship between satisfaction with transitional care and social and emotional quality of life over time. Satisfaction with transitional care included process aspects such as the responsibility of a particular staff member for coordinating each adolescent's care, the availability of a staff member to provide information about other people/organizations that could provide support (e.g., specialist career counselor, benefit advisor, support group), and staff members help planning for the future and prepare for the transition from child- to adult-oriented care. But also management of the environment (e.g. provide opportunities to meet other young people with the same chronic condition and display relevant health-related information in waiting rooms) and provider characteristics (e.g. availability of staff who understand the realities of being a teenager and who know how to talk and listen to teenagers) are important aspects of satisfaction among adolescents with chronic health conditions with transitional care (Dovey-Pearce et al. 2005; Shaw et al. 2007, 2004c; van Staa et al. 2011b). Hospitals and rehabilitation centers that provide care to adolescents with chronic health conditions should thus pay attention to these issues and try to implement interventions that aim to improve them. By implementing interventions such as individual self management plans and improving provider characteristics by training them in motivational interviewing may contribute to a better match between adolescents' needs and the care they receive. Furthermore, individualized self-management or transition plans are expected to stimulate adolescents to become more independent and to enhance their self-management and coping skills not only with respect to the physical aspects of their condition, but also with respect to the psychosocial aspects. Transitional care needs to better address the changing needs and roles of adolescents and their families. Interventions with a comprehensive focus on adolescents' needs and not just physical functioning only, are expected to improve social and emotional quality of life outcomes among adolescents with chronic health conditions.

Some limitations should be taken into account when interpreting our study findings. First, our group of adolescents with NMD was smaller than our other groups. Although our results are largely in agreement with those of other studies, they should be interpreted with caution due to this imbalance in our study sample. Second, although the response rate of 31 and 43 % might seem low, and there is the potential danger of non-response bias, it is similar compared to other studies in which the respondents also received a questionnaire by mail (Picavet 2001; Buttle and Thomas 1997). Finally, since this was not a randomized control study we found significant relationships between transitional care and social and emotional quality of life over time only, we could not identify the predictive nature of transitional care on social and emotional quality of life.

Strength of this study is that we investigated the longitudinal relationship between satisfaction with transitional care among adolescents with a variety of chronic conditions, while controlling for quality of life at baseline.

We conclude that greater satisfaction with transitional care is significantly related to better social and emotional quality of life among adolescents with diabetes, JIA, and NMD over time. Thus, the improvement of adolescents' transitional care in hospitals and rehabilitation centers is expected to be beneficial for their quality of life.

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Conflict of Interest We declare no conflict of interest.

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