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AN EXPLORATION INTO IDENTITY FORMATION IN YOUNG PEOPLE LIVING WITH A CHRONIC ILLNESS

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Summary of the MRP Portfolio

Section A critically reviews relevant theoretical literature and empirical studies exploring the particular impact of chronic illness on identity formation in adolescents. Theoretical conceptualisations of the adolescent period and of the process of identity formation are explored. Following this, empirical literature regarding the impact of chronic illness on the developmental tasks of adolescence and in particular identify formation will be critically examined. A number of clinical implications are discussed to enable clinicians to effectively support young people and future research directions are outlined.

Section B reports a narrative analysis of eight young people's experiences of forming an identity with a diagnosis of an adolescent-onset chronic illness. Two illness types were studied; crohn's disease and juvenile idiopathic arthritis. Semi-structured interviews elicited five narrative themes: Walking a different path, tolerating contradiction, a changed interface with others, locating power and a fluid relationship. Identity was considered to have been influenced by dominant social narratives concerning health and illness. Chronic illness was found to have significant, though not exclusively negative, impacts on developmental tasks. The findings are discussed in relation to existing literature and the clinical and research implications described.

Section C critically appraises the narrative study. A discussion begins with reflections on the research skills developed and insights into the research process. Areas of further learning are identified. Implications of clinical practice are explored and the section concludes with considerations for further research in this area.

Overall contents

Section A: Literature review

Section B: Empirical paper

Section C: Critical appraisal

Section D Appendix of supporting material

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SECTION A: LITERATURE REVIEW PAPER

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Contents Section A: Literature Review

Abstract

This review considers the particular impact of chronic illness on identity formation in adolescents. Given the important developmental tasks of adolescence it was considered important to explore in detail the impact of chronic illness for young people at the point at which issues of identity are developmentally most pertinent. It reviews relevant theoretical literature and empirical studies.

Key theoretical approaches differ in their conceptualisation of the process of identity formation but concur that it is during adolescence that issues of identity are developmentally most pertinent. The impact of contextual factors is explored. The empirical studies reviewed suggest that chronic illness complicates rather than alters the process of identity formation. Implications for social functioning were evident; managing the visibility of illness and engaging in attempts to keep it hidden impacted significantly on independence, risk-taking, responsibility and relationship development. Young people's appraisals of their illness played a significant role in how they defined their identity. Young people often skilfully managed the impact of CI. Opportunities for resilience and personal growth were found to have positive impacts for identity.

A number of clinical implications are discussed to enable clinicians to effectively support young people. Despite implications for development, and in particular identity formation, research examining adolescent-onset chronic illness has been notably sparse. Suggestions for future research are made including a fuller exploration of young people's experience of identity formation to capture the thoughts, feelings and meanings that these young people ascribe to their experiences**.**

Key terms: adolescence, chronic illness, development, identity formation.

Introduction

This review is an exploration about identity formation in young people living with a chronic illness (CI). It begins by exploring relevant theoretical literature and is followed with a review of empirical studies. Due to the scarcity of research this review will also include studies with adult populations. The review will conclude by identifying gaps in the research and will consider potential research and clinical implications. Given the important developmental tasks of adolescence and the way that CI can impact on an individual, it was considered important to explore in detail the impact of CI for young people. Research on CI has typically focused on adjustment to illness diagnosed during childhood and adulthood. Despite implications for adolescent development, research into CI onset during this period has been notably sparse (Holmbeck, 2002). This review seeks to explore the particular impact of CI on identity formation in adolescents. It aims to understand the role of CI and to consider if and how young people incorporate the diagnosis into their identity. Issues of incorporating a diagnosis into identity, at the point at which issues of identity are developmentally most pertinent will be considered.

Search Strategy

The search was complex given the difficulties in defining key terms as previously described. The strategy employed can be found in appendix 1. Ten works were included that related to theoretical perspectives. Twelve empirical articles were selected for review, five qualitative studies using semi-structured interviews, six quantitative using standardised measures and one mixed design. Four qualitative articles concerning identity in adults with CI were retained to supplement the adolescent literature as they reported transition and incorporation over time.

The articles were reviewed with the following critical framework in mind; the aim was to reach a balanced appraisal of the work. A clear definition of variables and terms

allowed the reader to clearly comprehend the work and avoided ambiguity. Consideration of the setting and sample enabled a judgement to be made concerning the representativeness of the sample or the possibility of transferring the findings to another context or participant sample. For qualitative work, the description of the setting was important to enable the reader to appreciate the context of the work and a clear account of study elements was necessary to understand how the interpretations were made (Caldwell, Henshaw & Taylor, 2005).

The merits and demerits of methods used, for example in data collection and analysis allowed the reader to consider biases and limitations of the data collected and the conclusions that were subsequently drawn. Components such as validity and reliability, or trustworthiness and persuasiveness were influential in determining the quality of the study. The structure of the papers were taken into account in terms of how the discussion was linked to the findings, whether the findings were generalisable or transferable, and whether the conclusions made sense in light of the data presented.

Adolescence

One of the challenges of studying adolescence is the definition of the time period it encompasses (Marcia, 1980). The start and end of adolescence is highly varied and non-specific. It can be defined according to age norms, broadly from 10-20 years of age. A more meaningful definition accounting for individual and cultural variability may relate to the developmental tasks that a young person seeks to achieve during this time. Adolescence is characterised by more developmental change than any other stage (Williams, Holmbeck & Greenley, 2002); some of these rapid and significant physical, psychological and social-role changes are specific to western societies.

The tasks faced during adolescence are complex and include the development of sexual identity, emotional separation from parents, identification with peers, physical maturation,

cognitive and moral development, and self-definition (Sterdevant & Spear, 2002). Adolescence is typically distinguished into three distinct phases; early, mid and late. Each has its own primary challenges or developmental tasks (Christie & Viner, 2005; Petersen & Leffert, 1995). Mid to late adolescence, the years from 14-16 years and from 17-20 years respectively, involve a growing reliance on internal values, development of personal identity and social autonomy (Christie and Viner, 2005). Self-definition is argued to begin in infancy with self-object differentiation yet key processes of self-definition take place during adolescence (Kroger, 2004; Marcia, 1980).

Identity

Marcia (1980) writes that 'identity is an even more difficult term to delimit than is adolescence' (p. 159). Identity has been described as "a person's essential, continuous self, the internal subjective concept of oneself as an individual" (Reber & Reber, 2001). Harter (1999) refers to the self-system, containing key components of self-evaluation, self-regulation and self-knowledge. Polkinghorne (1988) introduces the concept of time suggesting that the self is a configuration of "personal events into a historical unity which includes not only what one has been but also anticipations of what one will be" (p.150). Charmaz (1995) defines identity as the way in which an individual "defines, locates and differentiates self from others" (p. 659). Whether identity arises from internal developmental processes or is socially constructed and can be understood only in relation to the environment remains under debate (West, 2007).

The term identity formation has been selected for this review to reflect the nature of this dynamic process over time. It acknowledges the possibility that identity may be formed through internal processes and external influence.

Theories of identity formation

Theoretical approaches describing identity development have typically portrayed a systematic linear progression through a series of stages encompassing the various dimensions of change and growth.

Erikson's psychosocial model

Erikson (1959) conceptualised identity formation as the fifth task in an eight stage psychosocial model of lifespan development. A bipolar conflict at each stage must be resolved before progression to the next. Although stages are not defined by specific ages, identity formation, the crisis between identity achievement and role diffusion (lack of coherent identity), is a key task, distinctive but not exclusive to the adolescent period. A young person must engage in active exploration; continually identifying with people or roles they admire. The adolescent must then select the identifications which relate to their own interests and talents and amalgamate them to form an identity; orientating towards the future and committing to a system of personal values and specific ideologies. They simultaneously consider the questions of 'Who am I?', 'Where am I going?' and 'What am I to become?'

Erikson saw identity as a psychosocial phenomenon, rooted both within the individual and the communal culture. Identity depended on the way society identified the individual, together with a combined sense of uniqueness, consistency of self and psychosocial reciprocity between self-perceptions and those of others (Erikson, 1968).

Despite remaining one of the most frequently cited theories of identity formation Erikson's model of lifespan development has received criticism due to its focus on linear, progressive and universal tasks (Carr, 2006). The concept of identity is not especially well-defined, used to refer to both a structure and a process; for others this leaves the model particularly amenable for research (Kroger, 2004). Cultural and gender biases also exist, leaving the model applicable in only those contexts which allow for ideological, social and

vocational choice (Kroger, 2004). However, it highlights common features of adolescent development against which to consider the interface between various aspects of a young person's life and how this transition is negotiated.

Marcia's identity statuses

Marcia's methodological framework extended Erikson's dichotomy of identity versus role diffusion. He stipulated four statuses of identity: identity achievement, foreclosure, identity diffusion and moratorium (Marcia, 1980). Individuals are classified according to the presence or absence of a 'crisis' (decision-making period) and 'commitment' (extent of personal investment) to an occupation and an ideology. Identity achievement refers to those who have experienced a crisis and who pursue self-chosen occupational and ideological goals. Foreclosure, in contrast refers to those who are pursing parentally-selected goals and who have not experienced a crisis period. Those in identity diffusion have no current investment in goals whilst those in moratorium are currently in crisis and struggling to commit. Identity status has implications for and correlates with personality characteristics, social interactions and psychological well-being (Marcia, 1980).

Enabling empirical study and representing an objective and reliable measure, Marcia's identity statuses are used extensively in identity research. The framework has been criticised for failing to capture Erikson's theoretical conceptualisation of identity by its narrow focus on concepts of exploration and commitment (Kroger, 2006). Although initially theorised to develop through a standard linear progression, later research has suggested that identity formation is a more dynamic process (Meeus, 1999).

McAdams' life-story model

The life-story model of identity acknowledges that whilst an individual is unable to return to a previous developmental stage, they can be reshaped by their experiences. This

intra-psychic evolution can be told through story and narrative in a process of self-reflective thinking. Narrative identity refers to "an individual's internalised, evolving, and integrative story of the self" (McAdams, 2008, p. 242). To understand the process of identity formation is to understand how these narratives are created, how these stories are told to the self and to others and how they are applied to knowledge of self, others and the world (Singer, 2004). Identity reflects a quality of self-understanding (McAdams, 2001). The construction and sharing of stories of the self is a method of meaning-making and considered central to life transitions. Containing accounts of low-points, high-points and turning-points (McAdams, 2008), this model considers how people make sense of suffering and incorporate adverse life events into their identities. This integration into narrative identity can contribute to psychological well being (Charmaz, 1995; Singer, 2004).

Consistent with Erikson and Marcia, life-stories are increasingly believed to be constructed in adolescence (Habermas & Bluck, 2000). In contrast, rather than a clearly demarcated stage resolved in adolescence or early adulthood, the life-story model considers identity formation a life-long project (McAdams, 2008). It acknowledges that a person may carry with them many stories which are salient at different times, rather than assuming a single narrative incorporating all self-stories (McAdams, 2001).

The importance of context

Recent research has explored the role of context in identity formation (Adams & Marshall, 1996; Kroger, 2006; Yoder, 2004). Conceptualising identity as seeking a balance between the self and the surrounding social system necessitates consideration of contextual factors (Christie & Viner, 2005; Kroger, 2004). Context can be facilitating and support the young person to shape their identity or, as Yoder (2000) suggests, can hinder the development of a strong, stable and coherent sense of self.

Chronic illness as a context

The term chronic illness (CI) is used synonymously with chronic condition, chronic disease and long-term condition and applied to numerous diagnoses. Long-term conditions are defined by the Department of Health as "those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies."(DoH, 2008, p. 10). CI is used in this review, selected to reflect the subjective experience of disease (Tock, 2010); a disease which is life-long, incurable, requires a medical regimen, and places limits on activity.

A CI diagnosis can represent a significant life transition. Individuals describe feeling unable to connect with their pre-illness identity, experiencing a shift in roles and responsibilities as a result of a series of "biographical disruptions" (Bury, 1982, p. 167). These shifts, often occurring with each symptom change, need to be negotiated delicately to protect self-identity. Illness inevitably alters our perceptions of ourselves (Altschuler, 1997). Changes to diet, lifestyle, medication regimens, and exposing ones body to the scrutiny of others accentuates a loss of a predictable way of relating to self and others.

Individuals can begin to understand CI and to know their changed body and threatened identity within the context of disruption to and evolution of their life story (Murray, 2000). Frank (1995) tells of 'narrative wreakage' in illness whereby the individual tells self-stories to form or reaffirm a self. These stories take one of three forms; restitution, chaos or quest. Each reflects a different position, underlying plot and tensions. In telling these stories to others, relationships are also reaffirmed. A person's response to illness will be influenced by what illness means to them and to others around them.

Identity formation in young people with chronic illness.

Developmental tasks

Theoretically CI has been argued to have significant implications for the successful negotiation of the developmental tasks of adolescence (Spirito, DeLawyer & Stark, 1991). There are numerous reasons to expect increased difficulties in successfully achieving normative developmental tasks for example, increased absence from school or work due to illness or hospital appointments, academic performance influenced by fatigue or pain, and medical intervention (Seiffge-Krenke, 1998). The management of CI whilst of paramount importance to well-being is often in conflict with adolescent strivings (Williams, Holmbeck & Greenley, 2002). Achieving developmental goals can be of greater importance to the adolescent than managing health (Yeo and Sawyer, 2005). Empirically, Taylor, Gibson and Franck (2008) reviewed the experience of living with a CI in adolescence and found a consistent pattern of themes concerning developmental challenges. The authors reviewed 20 qualitative studies involving adolescents aged 10-19 years. Overarching themes were developing and maintaining friendships, being normal, importance of family, attitude to treatment, school experiences, relationship to healthcare and the future. Aspirations were constrained and relationship dynamics altered. Commonalities in themes across diagnoses were found suggesting that the experience is not disease specific. Similarities were found between young people with CI and healthy peers, suggesting that whilst illness does not alter development, it complicates it. Experiences of life with CI did however change according to developmental stage, suggesting a dynamic process.

As the first systematic review of how young people with CI perceive their lives and development, this review raises awareness of consistent themes emerging for this group. The study is limited by its selective inclusion of qualitative studies and the wide variety of

methodologies included. This review reports many themes theorised to be important aspects of identity in the developing adolescent.

Levels of identity exploration

Given that CI may complicate rather than alter the negotiation of developmental tasks, the following section includes empirical studies of the process of exploration; considered to be key to the identification of and commitment to identity alternatives. Hosek, Harper & LaVome Robinson (2002) explore how identity formation may be affected by the presence of human immunodeficiency virus (HIV) in eight adolescents aged 17-21 years. Semi-structured interviews combined standardised measures of identity development with open-ended questions to elicit personal stories of experience. Prolonged dependence on care-givers, increased parental monitoring, and uncertainty of disease prognosis were hypothesised as making it difficult to achieve a sense of identity (Hosek et al., 2002). For some, diagnosis of a life-threatening disease facilitated and expedited identity development. For others, identity exploration was inhibited. Commitment to goals and ideologies was avoided for fear of making plans that may not be realised. Identity status was found to impact on young people's response to HIV. Marcias' identity achievers demonstrated an awareness and exploration of thought processes and of their values and beliefs around having HIV. The authors hypothesised the increased identity development that these young people had achieved facilitated this process. Young people identified as having diffused identity status demonstrated apathy, ambivalence about death and thought avoidance.

HIV as a CI is a relatively recent consideration. The perceived life-threatening nature of HIV and associated stigma may have influenced this study; generalisability of these findings to young people with other CIs remains unclear. Whilst limited, Hosek et al. (2002) emphasize the importance of context and individual differences in the significant variety of ways in which HIV impacted identity development. A deeper level of identity exploration

may impact positively on the young person's response to illness; confronting and exploring illness can afford opportunities for personal growth.

Consistent with Taylor et al.'s (2008) findings Luyckx et al., (2008) found normality rather than deviance in identity development for young people with diabetes. Administering standardised measures of identity dimensions, depression and diabetes-specific measures of coping, they compared 194 young people aged between 18 and 30 years with diabetes to a comparison sample of 344 healthy peers. Luyckx et al. (2008) also found a lower level of exploration of identity issues in diabetic patients than in healthy peers; hypothesised as due to perceived constraints imposed by their diagnosis. A strong sense of identity was associated with higher levels of agency and competence, better coping and protection against diabetes related problems. The usefulness of these findings is limited by the use of single informant self-report measures which possess an inherent bias. A low participation rate suggests that the findings may not be representative of a wider group and should be generalised with caution. Longitudinal replication would allow exploration of the directional path identified in the data.

Overall, there appear to be individual differences in the way that CI impacts upon the process of identity exploration. For some, illness promoted explorations and new perspectives, whereas others felt constrained by their diagnosis.

Role of appraisal

The personal significance of illness, values and beliefs are influential factors in responses to CI. Several studies have indentified the importance of appraisals and attributions for identity. Hegleson & Novak (2007) explored illness centrality, or the extent to which individuals define themselves in terms of their illness, in early adolescents with diabetes. One-hundred and thirty-two young people aged 10-14 years completed standardised measures of illness centrality and psychological distress. Poorer psychological well-being was associated with illness centrality in females but to poorer metabolic control in males.

Appraisal of the illness was found to be important. When the experience of living with diabetes was perceived negatively and this was integrated into the self-concept so that the young females felt they were defined by their illness, psychological distress was common. This was particularly relevant when considering physical appearance aspects of self-esteem. When the illness was perceived as benign there were minimal psychological implications.

Different developmental timings for each gender were hypothesised to account for differences found. Girls can recognise contradictions within the self earlier than boys. Contradictions, such as that between ill and healthy aspects of the self, gave rise to adverse reactions, particularly within an illness experience that is regarded negatively.

Woodgate (1998) used grounded theory to elicit 13-18 year-olds' CI experiences. Twenty-three young people with a variety of diagnoses reported a dominant theme of 'It's hard'. Several subthemes emerged concerning the need for extra effort to overcome obstacles and to manage their illness, the experience and awareness of restrictions and limitations imposed by illness, pain, additional worry about health and consequences of their illness. Participants reported a sense of hopelessness, failure and guilt when unsuccessfully managing their conditions. Self-discipline in acknowledging limitations consequently left young people feeling different and not accepted by others.

Sparud-Lundin, Ohrn & Danielson (2010) interviewed 13 young adults and 13 parents, and collected data from an Internet communication site. Numerous threats to identity for young people with diabetes emerged, such as attributing weakness to self-medicating in public and failure when unable to maintain blood glucose control. The need for support challenged young people's view of themselves. Emerging adults demonstrated an increasing self-awareness of their own capacities through the integration of illness into their identities however they reported 'struggling with identity formation as an ongoing process' (Sparud-Lundin et al., 2010, p.133). The transfer of responsibility for self-care and independence,

changing relationships, increased self-awareness and threats to identity were acknowledged. The importance of social support was emphasised as necessary in clinical practice but the value of choice was recognised. For some young people, being grouped with those with similar illness experiences was helpful, whereas for others this challenged the construction of their identity. Differentiation of self from other is argued by the authors to be an important step in identity formation.

Overall, a negative perception of CI increases the potential for psychological distress, particularly in relation to physical appearance. Some young people attributed weakness, guilt and failure to the need for and management of medical regimens.

Social functioning

Whilst important to be aware and respect restrictions imposed by their illness, young people reported they consequently felt marginalised and different at a time of heightened self-awareness and peer-orientation. Variables such as visibility, bodily changes, and course of illness have the potential to interfere with or dictate particular social responses (Charmaz, 1990; McKinney, Schiamberg & Shelton, 1998). Implications for social functioning are discussed below.

Dovey-Pearce, Doherty and May (2007) interviewed young people aged 16-25 about the impact of diagnosis and living with diabetes. Participants experienced a shift in personal identity, influenced by a sense of being different, at the point of receiving a diagnostic label. This shift may occur even earlier due to the experience of an altered body preceding diagnosis. Changes in self-definition impacted on social experiences, reinforcing the initial shift in identity and promoting a new habitual way of relating to others. The study reports participants' ambivalence towards their condition, their struggle to integrate lifelong concepts of illness and mortality into their internal world and the age-appropriateness of the challenges they faced with the illness (Dovey-Pearce et al., 2007). Relationships with peers and family

appeared to be facilitating but could also hinder independence, privacy and autonomy. This study is valuable as it considers changes over time from diagnosis to living with diabetes. That personal identity emerged as one of the core themes from the semi-structured interview concerning development suggests that this may an important issue for young people with diabetes.

Using scores from standardised measures to explore psychosocial adjustment in adolescent-onset inflammatory bowel disease (IBD), Mackner & Crandall (2006) conclude that adolescents may be more at risk of psychosocial difficulties, specifically social functioning, than healthy peers. Social functioning, they argue, is a key component of developing independence and autonomy in identity development. No significant differences in behavioural, emotional or family functioning were associated with adolescent-onset. This study highlights the resiliency of young people with IBD but is limited in its use of parent-report of psychosocial adjustment.

Kashikar-Zuck, Lynch, Graham, Swain, Mullen & Noll (2007) consider the central role of peer relationships for development in 55 young people aged 12-18 years with juvenile fibromyalgia. Data on peer reputation and acceptance were collected from teacher, peer and self-report with no focus on CI. Young people with CI were rated by self- and peer-report to be more withdrawn, isolated and less popular. They had fewer reciprocated friendships than healthy peers. The study is limited by its selection of participants from clinical samples. These individuals are already help-seeking, representing only a portion of young people with CI; generalisability to non-treatment seekers is limited. Additionally, emotional well-being was not explored which may also have influenced peer relationships.

Reiter-Purtill, Gerhardt, Vannatta, Passa & Noll (2003) assessed social functioning using standardised questionnaire measures in 57 young people aged 8-15 years with juvenile rheumatoid arthritis (JRA) over a 2-year period. Peer, teacher and self-ratings at time 1

revealed no significant differences between young people with CI and healthy controls on measures of social reputation and social acceptance. Social functioning declined over time for young people with moderate/severe JRA. Ratings of how well liked they were declined. Those with active disease experienced more peer rejection than those in remission. Although this study benefitted from an appropriate control of healthy peers, the data was subjected to a multitude of statistical analyses. Interpretation should be made with caution until findings can be replicated. The study suggests that young people with CI are remarkably similar to their peers and display psychological hardiness.

Opportunities for personal growth

In addition to documenting difficulties, constraints and limitations imposed by CI, several studies also identified strengths and illness gains which impacted positively on identity. Illness centrality and integration of illness into an individuals core identity has been linked to course and outcome of chronic conditions. A strong sense of identity enabled young people with diabetes to select adaptive strategies of integrating the illness into their self-definition and to avoid dysfunctional strategies such as withdrawal, avoidance and passive resignation (Luyckx et al., 2008).

Identity transformations allowed for personal growth and increased self-awareness (Asbring, 2001; Hosek et al., 2002; Whitehead, 2006). Skills were acquired in prioritising and fitting illness into everyday life (Asbring, 2001; Woodgate, 1998). Many young people experienced increased self-respect through acknowledging the hard work and effort expended to manage their condition (Asbring, 2001; Woodgate, 1998).

Finding new interests, assigning positive outcomes and talking to other chronically ill people, is testament to people's efforts to maintain a positive sense of self (Abring, 2001; Whitehead, 2006). For many young people comparing the self to others in a similar situation represented a new baseline against which to compare oneself. Conversely, Loes Van Staa,

Jedeloo, Latour & Trappenburg (2008) report that comparing the self to healthy peers allowed children growing up with a CI to affirm their normality.

An appreciation of opportunities for personal growth for people with CI is encouraging and often absent in the literature. These studies suggest that individuals often skilfully manage and balance the impact of illness.

Differentiating aspects of identity

Biographic disruption is typically partial and calls for different levels of identity transformation in different arenas of life (Asbring, 2001). In 25 women, aged between 32-65 years, with a diagnosis of chronic fatigue and fibromyalgia early identity was lost at diagnosis and a new identity formed during adjustment to the illness. Asbring (2001) concludes that biographic disruption is most acute in work and social arenas but that differential change is evident. Some women maintained activities they considered important to their identity whilst allowing disruption to others. Loss of role emerged as a key response and accepting a new identity was a process of reconciliation. The data were collected in single interviews with participants and may have benefitted from longitudinal design to more fully explore the reconciliatory process.

The personal impact of rheumatoid arthritis (RA) for 26 adults was explored by Lempp, Scott & Kinsgley (2006). The physical impact of RA impacted on both the private and public spheres of identity. Difficulties in the private sphere included negotiating loss of role, difficulties in relationships and loss of identity as an independent person, now and in the future. In the public sphere, participants spoke about work roles, participation in social activities and experiences of stigmatisation and discrimination. Dealing with outdated perceptions of disability and intolerance were endorsed by younger participants (25-45 years). There were some difficulties that transcended both the public and private spheres; perceived changes in physical appearance, change in social roles and alterations of self-image

and identity. Personal sense of identity was often different to expectations of others. The qualitative methods used in this study allowed for a rich exploration of individual experience but rendered its findings not directly generalisable. The seemingly different experience of younger participants could have been explored in more detail.

Naemiratch & Manderson (2008) found that by maintaining a status of "healthy but", adults with diabetes separated their physical health from their social self. The qualification of "but", acted as a bridge between health and illness and ensured minimal intrusion. This study benefits from longitudinal and triangulated data sources over an 18-month period and highlights important clinical implications of successful condition management to identity construction.

Self-image was explored in adolescents (mean age 17 years) with diabetes and RA compared to healthy controls by Erkolahti, Ilonen & Saarijarvi (2003). The self-image of young people with well-controlled and moderate levels of illness did not differ from each other or from that of healthy controls. Chronically ill adolescents demonstrated better management of internal and external environmental pressures, social and family relations. They adapted better to their environment, demonstrated greater affective stability and belief in their ability to cope than healthy controls. Vocational and educational goals were constrained, thought to reflect difficulties in planning for the future. Chronically ill adolescents indicated a more negative body image; they worried about their health and were not proud of their bodies. None of these differences reached statistical significance and relied on a single administration of a moderately valid and clinically relevant self-report measure. It is unclear how these findings may differ for those with acute, severe and unstable illness.

Transitions and turning points

CI necessitates a number of transitions and turning points in the acceptance of and incorporation of diagnosis into identity. Baumgartner & David (2009) and Whitehead (2006)

have attempted to map the process of identity transitions and reconstruction over time by exploring the experiences of people living with CI. A three-stage process describes the incorporation of HIV/AIDS into identity in 14 adults aged 25-52 years in a qualitative study (Baumgartner & David, 2009). The process began with diagnosis affecting participant's self- and public perceptions. Acknowledging engagement in high risk behaviours prompted a more fatalistic view of the future. Fear of a changed future was also common. Advancing from this initial emotional response was precipitated by a turning-point. Participants reported change in cognition (knowledge that they were able to live with HIV), emotional support and a threat to the body (beginning medical intervention). Finally integration of the HIV identity prompted re-evaluation and a change in the salience of other identities over time, for example, work, relationship, and spiritual identities. Illness identity changed frequently with symptom change. This study validates the importance of turning-points and knowledge in the incorporation process in CI. As a qualitative study exploring the lived-experience of participants reflecting on the process of incorporation, involving participants in confirming data analyses increases the validity of these findings.

Whitehead (2006) describes identity transitions in a longitudinal study over 2.5 years using repeated interviews with 17 people aged 13-63 years with chronic fatigue syndrome and myalgic encephalomyelitis and their family members. In the acute stages of illness, participants adopted a traditional sick role characterised by total debility. In the medium term disability was re-appraised as a part of the total self, though participants described a circular movement between incapacity and a supernormal identity as they experienced disruption, particularly to their social identity. The longer term promoted a positive reconstruction of the self, linked to new insights, increased autonomy and self-governance. Elements of the previous identity are contained in the new self. It is not yet clear how a deeper level of insight and awareness is achieved by some but not all.

The CI's under study in both papers have an associated stigma. The Baumgartner & David (2009) study was conducted when HIV was considered a CI and participants in the Whitehead (2006) study all attended a specialist clinic that validated the meaning of their condition. It remains unclear how this trajectory of identity reconstruction may apply to others living with CI.

To summarise, identity transitions were found to occur over time, the illness identity becoming less central and a new altered identity constructed. These adult studies were included to promote an understanding of the process of incorporating CI into an established identity over time. The relevance of this to those in the initial stages of attempting to define and form their identity remains unclear.

Summary and Conclusions

This review sought to explore identity formation in young people living with CI. Theoretical approaches differ in their conceptualisation of the process of identity formation but concur that it is during adolescence that issues of identity are developmentally most pertinent.

The empirical studies reviewed suggest that CI complicates rather than alters this process. Key processes of self-definition occur over time involving exploration, commitment and self-awareness. CI during adolescence has implications for identity, precipitated by a number of transitions. Implications for social functioning were evident and young people's appraisals of CI played a significant role in how young people defined their identity. Presenting oneself as 'normal' was a key concern. Managing the visibility of illness and engaging in attempts to keep it hidden impacts significantly on independence, risk-taking, responsibility and relationships. Young people often skilfully managed the impact of CI. Opportunities for resilience and personal growth had positive impacts for identity.

Several studies argued that the particular diagnosis made little impact on identity formation, unless the diagnosis had a particular stigma associated with it. Young people are consistently expressing that it is the experience of having and living with a diagnosis of any CI that is important.

There are a number of methodological pitfalls within the previous research. Studies have not been consistent in the age range that they cover. Studies have adopted both qualitative and quantitative methods meaning that the concept of identity under study is inconsistent, leaving the findings difficult to assimilate.

Clinical and research implications

A number of clinical and research implications emerged. Clinically, the importance of understanding the developmental processes that young people negotiate during adolescence and of incorporating these developmental considerations into clinical practice is highlighted. Clinical psychologists should not let a lack of specific medical knowledge restrict them in working with these young people as research has shown that experiences are complicated but not altered by the presence of CI. Training across the lifespan should equip clinical psychologists to effectively support young people through this developmental stage where issues of identity formation are most salient.

Social support was important for identity formation in young people with CI. Time-sensitive interventions should be offered at key points, for example transfer to secondary school, recognising the necessity for choice; one cannot assume that one type of support will work for all.

Despite implications for development, and in particular identity formation, research examining adolescent-onset CI has been notably sparse. This review advocates longitudinal studies to explore change over time. Studies exploring potential gender differences may provide clinicians with useful information for meeting the individual needs of young people.

Comparative studies with healthy peers to explore the extent of the impact of CI may also be useful to examine why there is a lower level of exploration of identity possibilities. Young people may feel constrained by their illness; healthy peers may attribute this constraint to other factors such as parents or school. This particular group of young people may naturally demonstrate a lower level of identity exploration even in the absence of CI.

Adolescent-onset CI is a relatively new area of research (Holmbeck, 2002). Additional work is needed to understand the challenges for negotiating the developmental task of identity formation and concurrent diagnosis of a CI. Research has tended to rely on standardised self-report questionnaire measures. A qualitative exploration of young people's experience of identity formation would be sensitive enough to capture the thoughts, feelings and meanings that young people with CI ascribe to their experiences.

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**A narrative exploration of the impact of adolescent-onset
chronic illness on identity formation in young people**

SECTION B: EMPIRICAL PAPER

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Contents Section B: Empirical Paper

Abstract

Identity formation is argued to be one of the key developmental tasks of adolescence. Despite implications for adolescent development, research into chronic illness onset during this period has been notably sparse. This study aimed to explore how diagnosis impacts on the developmental tasks of adolescence, what role adolescent-onset chronic illness plays in identity formation, and how adolescents incorporate the diagnosis into their identity. Individual semi-structured interviews were carried out with 8 young people aged 14-19 who lived with a diagnosis of a chronic illness diagnosed between the ages of 12-16 years. Two illness types were studied; crohn's disease and juvenile idiopathic arthritis. Interviews were audio-recorded, transcribed and analysed using narrative analysis. Participant narratives contained five core narrative themes: Walking a different path, tolerating contradiction, a changed interface with others, locating power and a fluid relationship. Narratives were considered to have been influenced by factors such as the interview context and dominant social narratives concerning health and illness. Adolescent-onset CI was found to have a significant, though not exclusively negative, impact on developmental tasks. The findings are discussed in relation to existing literature and potential clinical implications.

Keywords: chronic illness, identity formation, adolescence, narrative analysis

Introduction

In western society, the adolescent period is characterised by more developmental change than any other stage (Williams, Holmbeck & Greenley, 2002). The tasks faced during adolescence are complex and include physical maturation, cognitive and moral development, and self-definition (Sterdevant & Spear, 2002). Receiving a diagnosis of a chronic illness (CI) during this time adds complication and demand to young people's lives. Research on CI has typically focussed on adjustment to illness diagnosed during childhood and adulthood. Despite implications for adolescent development, research into CI onset during this period has been notably sparse (Holmbeck, 2002). An exploration of the particular impact of CI on identity formation in adolescents is warranted.

The relevance of adolescence to identity formation

Several theorists agree that key processes of self-definition take place during adolescence (e.g. Erikson, 1968; Kroger, 2004; Marcia, 1980). Although there remains disagreement regarding the precise nature of this process, young people are thought to engage in exploration, orientation towards the future and commitment to a system of personal values, specific ideologies and occupation (Erikson, 1968; Marcia, 1980). Identity can be considered a psychosocial phenomenon, rooted both within the individual and culture. According to Erikson (1968), identity depends on the way society labels an individual, together with a combined sense of uniqueness, consistency of self and psychosocial reciprocity between self-perceptions and those of others.

Rather than a clearly demarcated stage, resolved in adolescence, narrative models of identity view individuals as being reshaped by their experiences (Habermas & Bluck, 2000; McAdams, 2001). Identity is considered to reflect a quality of self-understanding (McAdams,

2001). Narratives or stories are created by individuals, told to the self and to others, and applied to knowledge of the self, others and the world (Singer, 2004) as a way of making meaning. The construction and sharing of stories of the self is also considered central to life transitions.

Identity and chronic illness

A CI diagnosis can represent a significant life transition. Individuals describe feeling unable to connect with their pre-illness identity, experiencing a shift in roles and responsibilities as a result of a series of "biographical disruptions" (Bury, 1982, p. 167). Illness inevitably alters our self-perceptions (Altschuler, 1997). Changes to diet, lifestyle, medication regimens, and exposing ones body to the scrutiny of others accentuates a loss of a predictable way of relating to self and others. Charmaz (1995) and Bury (1982) suggest that CI assaults the body and threatens integrity of self by disrupting a sense of wholeness between body and self. Charmaz (1991) writes that in experiencing CI an individual moves from having a life interrupted by illness, to a life intruded by illness, to a life immersed in illness. Identity questioning often occurs at this latter stage as individuals engage in a process of acknowledging identifications of the self in their present illness experience, comparing with past identities and predicting a future self. In her work with adults with a variety of CI diagnoses, exploring narrative accounts of illness experiences, she articulates struggles with identity coherence and continuity.

Narratives and stories of identity in chronic illness

There has been a growing literature on illness narrative and narrative identity (Reissman, 2004) where the subjectivity of illness experience is acknowledged and the stories individuals tell contextualise and explain their interrupted lives. The physical and psychological changes evoked by an illness experience often create a sense of discontinuity

in identity (Rimmon-Kenan, 2002). Individuals are argued to begin to understand CI and to know their changed body and threatened identity within the context of disruption to and evolution of their life story (Murray, 2000).

Frank (1995) writes of 'narrative wreakage' in illness whereby the individual tells self-stories to form or reaffirm a self. These stories take one of three forms; restitution, chaos or quest. Each reflects a different position, underlying plot and tensions. In telling these stories to others, relationships are also reaffirmed. A person's response to illness will be influenced by what illness means to them and to others around them.

Goffman (1969) asserts there are performative purposes to illness narratives in presenting a desirable self, preserving 'face' in difficult situations like CI. These performances are influenced and constrained by social structures and dominant narratives. Researchers must attend to both what is told and the manner of telling (Reissman, 2004).

The experience of chronic illness in adolescence

Risk factors for identity have been implicated within the research literature such as loss of role, an uncertain future (Charmaz, 1995), lifestyle changes and exposing ones body to the scrutiny of others (Altschuler, 1997). Risk factors may have the greatest impact during complex transitional periods, such as adolescence (Mackner & Crandall, 2006). CI has significant implications for the successful negotiation of the developmental tasks of adolescence, including identity formation (Spirito, DeLawyer & Stark, 1991). Despite this, research into CI onset during this period has been notably sparse (Holmbeck, 2002).

In children growing up with CI, the normalisation of an unhealthy childhood appears to influence identity formation in adolescence. Children compared themselves favourably to healthy peers, controlled disclosure of their CI and endeavoured to prevent their illness from dominating their lives (Loes Van Staa, Jedeloo, Latour & Trappenberg, 2008). Psychological distress was common in young people when the experience of living with diabetes was

perceived negatively and this was integrated into the self-concept (Hegleson & Novak, 2007). The authors suggest that making illness less central to the self-concept preserves self-esteem. Poor self-concept is not a necessary outcome (Erkolahti, Ilonen & Saarijarvi, 2003). Young people with well managed CI did not incorporate an illness self-image but experienced themselves as healthy despite their illness. Consistent with previous findings, the duration of illness was not associated with self-esteem. This research informs us about how identity may be influenced by CI for those young people for whom this is a familiar illness experience. It does not add to our understanding, however, of how identity formation may be influenced by the onset of CI at a time when issues of identity are most salient.

Three studies have focused specifically on adolescent-onset CI. Mackner & Crandall (2006) found that adolescent-onset inflammatory bowel disease had specific implications for social functioning. Reduced social competence and participation, together with difficulties coping with disease symptoms were considered to be important influences in identity formation. Despite the authors' efforts in asserting the need for work in this area, this study is disappointing due to its use of single-method parent report. The perspectives of the young people are neglected and the communication of their experiences constrained by the limited nature of the assessment tools used.

In another study comparing young people aged 18-30 with adolescent-onset diabetes to a sample of healthy peers, those with adolescent-onset CI were found to follow the same process of identity formation as healthy peers. For some, however, an inhibited level of identity exploration was observed (Luyckx., Seiffge-Krenke, Schwartz, Goosens & Weets, et al., 2008).

Finally, Hosek, Harper & LaVome Robinson (2002) found variance in levels of identity exploration. For some, exploration of identity alternatives was inhibited; commitment to goals and ideologies avoided for fear of making plans that may not be realised. For others,

diagnosis facilitated identity development. The authors explored how identity formation may be affected by the presence of adolescent-onset human immunodeficiency virus (HIV) in eight adolescents aged 17-21 years. Standardised measures of identity development were combined with interviews to elicit personal stories of experience. Hosek et al. (2002) found that an increased level of identity development facilitated young people's awareness and exploration of thought processes and of values and beliefs around having HIV. Similarly, Lucykx et al. (2008) observed that the benefits of a strong sense of identity were associated with higher levels of agency and competence, better coping and protection against diabetes related problems. Prolonged dependence on care-givers, increased parental monitoring, uncertainty of disease prognosis (Hosek et al., 2002) and perceived constraints imposed by their diagnosis (Luyckx et al., 2008) were hypothesised as making it difficult to achieve a sense of coherent identity.

Single informant self-report measures possess an inherent bias limiting the usefulness of these findings. They may not be representative of a wider group and should be generalised with caution.

The present study

The aim of the present study was to better understand the experience of identity formation for young people with adolescent-onset chronic illness. The specific research questions were:

a) How does diagnosis impact on the developmental tasks of adolescence (independence, separation, forming social relationships, establishing future aspirations)? In what way?

b) What is the role of adolescent-onset chronic illness in identity formation?

c) How do adolescents incorporate their diagnosis into their identity?

Method

Choice of methodology

Narrative analysis (NA) was used in order to explore the experiences of identity formation in young people who receive a diagnosis of a chronic illness during the adolescent years. Murray (2003) suggests that the process of re-counting experience allows an opportunity for participants to re-construct themselves and as such is a suitable method for the study of identity in relation to chronic illness. This was considered to be particularly relevant in exploring how young people negotiate the task of identity formation. Other qualitative methods were considered.

NA is an umbrella term and as such there is no unified method of conducting the analysis (Andrews, Squire & Tamboukou, 2008; Dallos & Vetere, 2005; Reismann, 1993). NA is being increasingly used in the field of health psychology. This study adopts an analysis framework which draws upon a number of narrative methodologies used by other researchers in the field (Delmar et al., 2006; Ohman & Soderberg, 2004).

Epistemological position

NA is part of the social-constructionist paradigm (Crossely, 2000), which considers narratives to be versions of lived-reality, constructed through language, rather than representing an 'objective truth'. Reality and meaning are thought to be co-constructed between individuals, embedded within a historical, social political and cultural context (Burr, 1995). This study adopts an experience-centered approach assuming that narratives are sequential and meaningful, re-present experience and display transformation and change (Squire, 2008).

Participants

Participants aged between 15-19 years (mid-late adolescence) with a diagnosis of a life-long and incurable medical condition that places limits on social, physical, and/or work activities, were recruited. Diagnosis had to have occurred at least one year before entry into the study. A number of exclusion criteria were applied in order to protect vulnerable potential participants. These included: multiple physical health problems, a learning disability, identified as a child in need or subject to a child protection plan, current psychiatric involvement for mental health difficulties or without a good command of the English language. These variables were considered to have their own potentially significant impacts on a young person's identity and would make it difficult to meet the aims of the current study exploring the particular impact of chronic illness.

Participants were recruited from an NHS Child and Adolescent Medical Service. A purposive sampling technique was employed and eligible participants, identified with a clinical nurse specialist, were sent a letter inviting them to take part and an information sheet giving details of the study (appendices 4 and 5). For those young people under the age of consent, letters of invitation and information sheets were sent to their parent/carer (appendices 6 and 7) and additional information sheets enclosed for the young person.

The narrative approach makes no claims of generalisability. Pre-determined sample sizes are rarely stipulated and sampling is more often based on theoretical and opportunistic grounds (Squire, 2008). A total of eight young people participated in the study with a mean age of 17.1 years (range 15-19 years). Four participants were female and four were male. Mean number of years living with diagnosis was 3.5 years (range 2-7 years). Six participants were White British and two British Pakistani. Five participants had a diagnosis of Crohn's disease and three, juvenile idiopathic arthritis. Table 1 contains information about participant characteristics. The inclusion criteria of age at diagnosis was relaxed for two participants (*)

as it emerged that there were difficulties ascertaining the actual age of diagnosis rather than symptom experience.

Table 1: Participant demographics

Name (Pseudonym)	Age	Diagnosis	Age at diagnosis	Years living with diagnosis
Elizabeth	19	Ulcerative Colitis/Crohn's	14	5
Melissa	17	Juvenile idiopathic arthritis	15	2
Clare	15	Crohn's disease	12*	3
Jack	16	Crohn's disease	13	3
Alexander	19	Juvenile idiopathic arthritis	12*	7
Elena	17	Crohn's disease	14	3
George	16	Crohn's disease	13	3
Oliver	18	Juvenile idiopathic arthritis	16	2

Note: Pseudonyms have been used to protect participant identities

Interviews were conducted in the hospital setting where the young people received their medical consultations and lasted an average of 34 minutes (range 20 to 56 minutes).

Materials

A semi-structured interview schedule (appendix 9) was developed in consultation with a clinical psychologist working with young people with chronic illness and based on previous work in the area (Wilson, Pistrang, Woodhouse & Christie, 2007). A pilot interview was carried out to ensure that the depth and type of questions was suitable and adjustments made accordingly.

Interviews were conducted where possible in a conversation style as recommended by Riessman (2008) in order to minimise the researcher's impact on the narratives elicited. In

practice, prompts were used to introduce topics and detailed accounts of participant's experiences with these topics were sought. Adolescent interviewees present "unique opportunities and dilemmas" (Elder & Fingerson, 2001, p.181) for the researcher. Attempts were made to structure the interview accordingly; beginning with unstructured questions, using participants own language in reflections and paraphrasing to encourage elaboration and creating a natural context by interviewing in an environment with which participants were familiar.

Ethical procedures

Ethical approval was obtained from an NHS research ethics committee and the BPS Code of Conduct and Ethics was followed throughout each stage of the research. Participants over the age of 16 years gave verbal and written consent to take part (appendix 7). Those participants under the age of 16 gave written assent (appendix 7) and additional parental consent was given (appendix 8). Interviews were digitally recorded and transcribed verbatim with identifying information removed.

Data analysis

This study adopts a four stage analysis combining elements of both holistic-content and categorical-content analysis (Lieblich, Tuval-Mashiach & Zilber, 1998) to consider the transcripts as a whole and then as individual parts. Based on Ricoeur's (1991) phenomenological approach, analysis began with a naive reading of the transcripts to gain a sense of the material and a holistic understanding of the content. Interview transcripts were read several times and audio recordings listened to. This was taken together with initial researcher reflections and responses made at the time of interviewing the participants.

The second stage of analysis was to conduct a literary analysis to identify four key narrative elements which are well documented within narrative research (Crossely, 2000; McAdams, 1993; Murray, 2003). This allowed the researcher to consider each individual

narration whilst enabling initial patterns between participants to emerge. Narrative elements of tone, core narrative, genre and positioning were identified.

Narrative tone is conveyed in both the content of what is said and in the form in which it is told (Crossely, 2000; McAdams, 1993). This enabled emotional information to be captured and provided a context for the narrative. Core narrative is described as drawing out and summing up the main story of each narrator (Mishler, 1986); an established method within NA. Narrative genre captures the kind of story the participant is telling and conveys to the audience how they should interpret it (Squire, 2005). Positioning helps to develop an understanding of what the narrator was hoping to achieve by telling the story.

The third stage of analysis was a structural analysis, again based on Ricoeur's (1991) approach and involved describing the data thematically. The analysis of key themes is one of the central components of NA. Themes are thought to cluster around recurrent content in narrative accounts (Lieblich et al., 1998). Transcripts were re-read and narrative segments related to the research questions were identified. These segments were initially grouped into thematic codes using a constant comparative method (Glaser & Strauss, 1967). These codes were then considered across all participant narratives and in relation to the entire transcript to capture context and intended meaning. They were re-organised and re-named in order to synthesise the data into categories that were coherent whilst capturing the diversity of data across all participant narratives (Lieblich et al, 1998).

Finally a reflective reading was conducted which allowed consideration of all previous stages of analysis together with the researcher position and potential influences. Following the work of Murray (2000) in the field of health psychology, levels of influence on the narratives told were considered. Murray (2003) argues that the structure of narrative accounts is not fixed, but rather depends on a variety of factors including the narrator, the audience and the broader social and cultural contexts.

Quality assurance

A reflexive stance was assumed to consider the influence of the researcher in the interviews and data analysis. A self-reflective interview (appendix 10) was conducted prior to embarking on the interview stage and notes were made subsequently following each interview. Given that the principle researcher lives with a diagnosis of chronic illness, this facilitated bracketing; allowing awareness of biases so their influence on the research process is minimal (Ahern, 1999). A reflective journal was kept to provide a transparent account of the researcher's subjectivities during the research process (appendix 11).

Respondent validation was not sought as NA seeks to deliver the researcher's account of the respondent interview (Reissman, 1993). The possibility of alternative readings and consensual validation were explored in supervision in order to enhance the trustworthiness of the interpretations made.

Results

The results will be presented according to: i) a narrative summary for each participant, ii) the five narrative themes that emerged and iii) a consideration of the influences on the narratives told.

Narrative summary for each participant

An example of the literary analysis is contained in appendix 15 and a table of the literary elements identified for all participants within appendix 16. Below are summary narratives, for each participant, included to give context for the proceeding analyses.

Elizabeth's narrative of post-traumatic growth

Elizabeth's narrative portrayed an epic journey, capturing impressive struggles, adventures and great efforts over long periods of time, "I think it's fantastic that I have

Crohn's...because although there are horrendous sides to it I have done so many things I probably would never have done in my life" (lines 166-168). In telling her story Elizabeth sought validation and celebration of her difference, her independence and her strength. Chronic illness clarified her priorities of what was important in her life.

Melissa's narrative of vulnerability

Melissa's core narrative was one of vulnerability. She experienced her illness as a tragedy, seen as a tragic flaw. She spoke of her efforts to hide her illness; feeling ashamed and burdened. She tried to ignore her diagnosis, feeling unable to hold in mind and consolidate the perceived contradictions between her well and ill self, "I think it brings out a kind of vulnerability in me that I don't want to see. I don't want to come across as being weak and vulnerable because I am quite....you know a loud and energetic person" (lines 330-333).

Clare's narrative of the need for focus and commitment

Clare's narrative contained an explanation of her need for focus and commitment to overcome hardship, and to maintain life as it was known to her prior to chronic illness. She managed but it was tough. She also spoke of contradiction in terms of attempting to minimise the effects of illness and of always being reminded of it, "I think as I've got older, it has become easier to be with... every time I forget, it always kind of nudges me that it is still there, it won't go away" (lines 308-316).

Jack's narrative of stoic acceptance

Jack's narrative communicated stoicism and acceptance that his illness was not something "you can do anything about or not deal with" (lines 290-291). The impact of his illness on his life is communicated in a description of a turning point where his illness became well-controlled by medication, "It sort of ruled me because I was ill... but now I can be myself" (lines 196-197).

Alexander*'s narrative of* conflict

Alexander's narrative captured a position of conflict. Although, like Elizabeth, he spoke positively of the "life experience" (line 203) he has had, his use of an almost melodramatic exaggeration and what felt like a rehearsed narrative suggested some ambivalence between his sense of failure to achieve previously set goals and his welcoming of chronic illness. Alexander maintained separation between his identity and his illness. Like Jack, he suggests that now his condition is well-managed by a medical regimen and feels like he no longer has it.

Elena's narrative of adapting

Elena's narrative captured a journey of learning. She spoke about confronting the chronicity of her illness, "It was a different sort of experience trying to accept it wasn't an easy fix" (lines 357-359). She communicated her journey in understanding how to live with her illness and make compromises rather than trying to fit it around her previous life, "I had to learn that I can't choose. I just had to accept it is what it is and just kind of deal with it rather than kind of putting it off" (lines 370-371).

Geo*rge's narrative of* taking a different perspective

In George's narrative the importance of being normal and of being the same as others was emphasised, "I like things to be normal I guess. I like things to go on normally. I like people not to make a fuss." (lines 296-300). The "normal everyday things" had become much more important. Like Elena, George spoke of how understanding his illness had helped him to think about it, "I'm pretty clear about what's going to happen" (lines 264-265).

Oliver's narrative of sameness

Oliver's narrative is similar in that it communicates efforts to maintain life as it was known. His narrative contained elements of adventure describing risk-taking and the pursuit

of exciting experiences but also elements of tragedy as he anticipated distressing losses as a consequence of his illness. His overarching message was of living alongside his illness and of not being changed by it. He worked hard to establish his sense of being a young person who is the same as others, "Right now I'm doing alright. I'm not going to let it bother me...especially at this age. I'm supposed to be having fun" (lines 146-148).

Narrative themes

Initial coding resulted in the identification of 44 initial codes (see appendix 17 for an example of structural analysis and appendix 18 for initial codes). Some were combined and others disregarded leaving five key themes (see appendix 19). The significance of themes was determined by, for example, the enthusiasm with which participants spoke, those topics which they found particularly difficult to talk about, and those topics spoken about most frequently or returned to throughout the narrative accounts.

Theme one: Walking a different path

Although participants responded to their diagnosis in different ways, all spoke of elements of transformational change. For some it concerned negative aspects of living with a changing body, a part of which did not work properly, for others it was a change in plans and anticipated pathways for the future.

> "*I'm not quite sure what I would have done if I hadn't of had arthritis. I'm not quite sure how my life would have worked out. I just... probably I would have finished school already and be at university, but would I trade that for the life experience I have had? Probably not*" (Alexander, lines 311-313).

Whilst not denying there were difficulties and restrictions, there was a strong narrative of embracing new opportunities that diagnosis had offered. Elizabeth, Alexander, Melissa and Oliver all spoke of feeling like they have missed out on experiences and

activities due to their illness, of wanting to seize new opportunities and make the most of their time.

> "I think life is the most important thing and appreciating *it, and actually living it. I've* done so many things this year, because I said to my Mum, I want to experience lots of things because *I've been in hospital for too long. I went paintballing, which Mum was* very apprehensive about, it did leave me ill afterwards, b*ut still it was fun"* (Elizabeth, lines 671-674).

Other participants also described how CI had facilitated growth and promoted independence, responsibility, confidence, resilience and an awareness of personal limits. Elena described how helpful it was to know her limits when managing her condition,

> "*I'm maybe slightly more reserved, just about em, em starting activities,* knowing more... kind of, knowing when my limit is ...I think I would still be the same,(pause) but maybe yeah, maybe its knowing myself a bit more, about when..... I know where my limit is.. (Elena, lines 279 – 313).

Another transformational narrative emerged as participants described a new perspective on what was important in life. Elizabeth, Clare, George and Melissa all told stories about how small activities that they had previously taken for granted had now become valued.

> "*Things have become more...more of a ...it feels better to do those things.... they've* become more important the things, everyday life things like having a meal, watching a *film things like that. They're become more important now..."* (George, lines 389).

Theme two: Tolerating contradiction

Four participants spoke with difficulty of the necessity to tolerate multiple levels of contradiction, one of which was between public and private aspects of their diagnosis.

Participants spoke of preserving a public face in order to avoid or minimise negative judgements from others that linked their health status with their identity. Whilst Clare and Melissa spoke of efforts needed to hide their condition from others, Jack and Elena spoke of the ease at which they were able to do so facilitated by the invisible nature of their illness.

The contradiction between the healthy-self and ill-self was interwoven throughout accounts. By controlling disclosure, Melissa was able to manage her perceived contradiction between her sense of being an energetic young person with a sense of herself as weak and vulnerable within her illness. In a similar way Alexander also voiced his experience of tolerating contradiction by maintaining distance from the impacts of an illness that he considered as a challenge to his sense of feeling 'normal',

> *"If I was going to look at myself from outside, I'd say I'm* pretty much cured of the disease. I mean I st*ill have it officially but I never get a flair. I'm pretty much normal* apart from [details particular aspects of his illness symptoms]...I am pretty much a *normal person now."* (Alexander, lines 87-92).

Representing illness as part of their body that no longer worked and required medical management presented a challenge to then view that as a part of the self. Oliver and Melissa narrated this struggle movingly,

> *"So I was like it's a part of me now, I can't do anything about it...cause I had to take* these ta*blets everyday and stuff. So it can't be separate thing, can it?"* (Oliver, lines 429-430)

> *"A*t the end of the day it kind of like (pause) theoretically it is like kind of a part of *me, because it's in my body. It's in my system and all of this stuff is happ*ening but I *don't see it. But, in my eyes I don't see it as a part of me because I don't want it to* be.*"*(Melissa, lines 548-550)

Perhaps the most salient and powerful contradiction spoken about by four participants concerned time and conflict between the present and future. Tolerating this contradiction in terms of managing his condition and progressive deteriorations whilst making great endeavours to preserve his sense of being a young person was spoken about by Oliver,

"I just thought, 'You know I'm doing alright right now'. I just.... if the worst comes to the worst I'll just... something like.... I've no idea, but I'm not going to let it bother me now. Especially at this age, I'm supposed to be having fun and stuff like that" (Oliver, lines 146-149).

Theme three: A changed interface with others

Six participants spoke about changed interactions with others, highlighting the public matter of living with a CI. Worries about the perceptions of others were evident in three accounts where participants referred to experiences of guilt, embarrassment and shame. Melissa spoke of her embarrassment of having an illness, which she associated with old age and immobility, and of her efforts to hide her condition from others.

Oliver's narrative conveyed concerns over his friendships. He subtly referred to his relief that his friends still wanted him around, suggesting that relationships with others felt more fragile than before. Clare and Elizabeth's narratives echoed this fragility,

"All my mates are really good mates and don't want me to like be in a wheelchair or something...been a couple of years now and they still want to hang around with me." (Oliver, lines 247-250)

Linked to this, was a conscious awareness of not being seen to use chronic illness as an excuse to not participate. Although there were differences between participants' experiences, the interface with others was paramount in their stories. Clare worried about friends feeling let down, Elena acknowledged how the long-term nature of her condition

impacted, but struggled to articulate why, as she perceived, her reasons for not participating were deemed less valid or acceptable as a result.

> *"*I didn't really want to use that [CI] as an excuse not to do certain things, because *it's like a long term thing, it's not like 'Oh I was ill for a week with a cold'. I think if you're constantly like 'No I can't because of this' over such a long time it feels more of an excuse, I think some people..., I don't know, it could be viewed more as an* excuse rather than....., and its hard to understand obviously *when you don't have it yourself."* (Elena, lines 247-253)

The value of positive social endorsement, especially in validating the efforts that participants had expended to manage their conditions was a feature in several narratives but particularly salient for Clare. She returned several times to the idea of others noticing her improvements and efforts and of admiring those who had been able to overcome similar experiences. She relied on feedback from others to validate and motivate her to work hard.

The interface with others was changed in terms of the expectations placed on participants. Participants were placed in juxtaposition between assuming a premature sense of adulthood and a state of childlike dependence. They were expected to relate and communicate with medical staff, to articulate their needs, manage often complicated medical regimens, asserting their independence. Simultaneously, they relied on parents and family to support them, to explain their conditions and to help them manage its impact, sustaining their state of dependence.

Theme four: Locating power

A narrative of power was evident in every account but manifested in different ways. For some it concerned a sense of agency and control through the accumulation of knowledge to increase understanding, enabling choice and reducing uncertainty. Four participants spoke

about their search for a causal explanation. Denouncing personal responsibility by identifying a cause, such as shock, a disease process, or a virus, appeared to offer Alexander and Clare some protection from the guilt that Melissa experienced,

> *"...cause due to leaving it so late* [to go to the doctor] has decreased the chances of it *being able to go away completely"* (Melissa, lines 230-232).

Adopting this self-blaming position appeared to lead Melissa to experience difficulties in incorporating her diagnosis into her identity. Where the cause of the CI was attributed to an external source, participants appeared to adopt a more stoic acceptance. This search for a cause also served as a driver for determination. This promoted an attitude of expending great efforts to overcome the impacts of their diagnosis. This drive was evident in all participant narratives.

There was a distinction between those participants who spoke of struggling against or with their illness. Clare spoke of struggling against her illness, positioned as the enemy, and of her great efforts to overcome its impacts. Other participants like Elizabeth and Elena, spoke more of a struggle with their illness. Their efforts were to keep their bodies functioning in order to maintain activities as much as possible. It was within these accounts that a switch in the location of power was tolerated in terms of being responsive and adaptive to their illness. Jack and Melissa narrated this struggle,

> *"It sort of ruled me... But now I suppose the medication works, now I can be myself"* (Jack, line 196).

> *"I just find it hard that like I can't live a normal life but with the additions of taking* tablets and self-*injecting"* (Melissa, lines 298-299).

Theme five: A fluid relationship

There were mixed narratives about the evolution of the relationship that young people had with their illness over time and the impact that this had on how they saw themselves. All participants spoke of a sense of permanence, of living with a condition that was always there,

> *"...it is always just there tagging along with you in a way. It's just like... like a lingering smell, that you can't get rid of it. It's just there...and kind* of sticks around you*"* (Melissa, lines 522-524).

Oliver communicated his sense of sameness, but with the addition of his CI diagnosis,

> *"it's just the same, its just that I've got arthritis now and I've always got arthritis now"* (Oliver, lines 177-178).

Elizabeth, Alexander and Oliver told stories of an attachment to their illness and viewed it as an important, though not necessarily a welcome part of them. They used language such as *"its' how I am, it's what I am"* (Alexander, line 408), *"...it's a part of* who I *am"* (Oliver, line 420). Similarly, other participants like George spoke of his unconscious awareness of his diagnosis, of not remembering a time before it,

> *"Yeah, at the beginning it was a bit.... at the beginning it felt like a quite a major* thing *but now it's kind of...., I can't really not remember not having it now in a way, so...."* (George, lines 377-380)

Elena suggested that in the early days following diagnosis, her condition became all consuming, she told a story of how she would not necessarily notice the individual symptom impacts as she was just focussing on "getting through it". The inconsistencies in Jack's stories of the relationship he had with his CI communicated the fluidity of this relationship over time. At times his diagnosis would overshadow many others aspects of his life, whereas at other times he described not being consciously aware of it,

"You get used to it plodding along with you I suppose." (Jack, lines 223-224)

Several participants communicated a move beyond initial difficulties in accepting the permanence of their condition to a position of understanding their relationship with it. Participants spoke of a dynamic relationship, of the need to be adaptive, and to prioritise their illness as necessary. Elena moved from attempting to fit her illness around her life, for example, scheduling appointments so as to not miss school, to a position of prioritising her illness.

"You have to realise that em, you just have to kind of deal with that as it comes. Em, and em, kind of, you have to, in a way you have to make it your priority and fit everything else around it especially if you want it to be sorted out quickly. ...You have *to make it a priority rather than leaving it and leaving it"* (Elena, lines 382-386).

Flexibility was also communicated in Jack's story of "having a lot of balls to juggle" (line 358), he managed the complexity of his life with CI by "at times dropping the other balls" (line 359). Similarly, Oliver communicated passionately his ambivalence in his relationship with his diagnosis. He told stories of forgetting his diagnosis and of pushing it to one side to allow him to enjoy life as a young person. Alternatively he was mindful of his future and anticipated a changing relationship,

"...worry about it, but not worry too much about it. Because right now you've got some time, but it's not..... it's not going to get very bad overnight" (Oliver 443-445).

Despite the chronicity of their illness and the psychological permanence that participants voiced, three participants (Oliver, George and Jack) spoke of seeing their diagnosis as one part of a bigger self. They described strategies to maintain other parts to their identity, for example,

"I'd kind of, er, well don't let it take over your life I guess. Do other things...Take other interests, do some studies, take some relaxation time I guess." (George, lines 456-461).

Levels of influence on narratives told

Narratives were also analysed as social performances and a number of influences emerged. Interpersonal and positional levels of analysis assume narrative to be a joint construction between the narrator, the listener and the context within which it is told (Murray, 2000). The influence of the interview context, within a familiar hospital setting, on the stories the participants felt they were able to share was evident in many of the participant accounts. For example, all of the participants spoke positively without prompting about the care they had received from the clinical team. This may have reflected the dominant voice of the medical model. Elizabeth, Alexander and Melissa spoke of alternative influences on their health such as the role of religion and positive thinking.

Emerging narratives positioned participants as having to justify their sickness to claim worthiness as fit participants in the social world. Participants were influenced by the identifications imposed on them by others. A dominant narrative of a life with illness representing a life of less worth emerged in accounts of struggles against illness and efforts to hide their diagnosis. Participants spoke of others pitying them, laughing at them, and of feelings of shame, embarrassment, weakness and vulnerability.

"I just don't want people to know about it because I don't want them to think that you know, I have to get... I don't like the thought of people knowing that I self-*inject"* (Melissa, lines 366-369).

Dominant social representations were also evident in participant's comparisons to other illnesses they deemed as more problematic, such as cancer or paralysis. Only Melissa appeared to challenge this dominant narrative by validating her personal experience,

"I mean, it's nothing compared to cancer or anything, but at the same time on a level of me having this and not knowing what it's like to have cancer, it*'s hard for me, because it's something I'm experiencing"* (Melissa, lines 321-323).

Discussion

This study explored the impact of adolescent-onset CI on developmental tasks of adolescence and in particular, identity formation. The findings will be discussed in relation to the research questions and in reference to existing literature. The section concludes with a discussion of the study's strengths and limitations, directions for future research and clinical implications.

How does adolescent-onset chronic illness impact on the developmental tasks of adolescence?

We know from the existing literature that adolescence is marked by significant developmental change (Williams, Holmbeck & Greenley, 2002). Participants narrated a number of developmental issues and multiple impacts on their experience of adolescence as a result of having a CI. Stories were told of restriction, changes in anticipated plans, maintained dependence on others and of increased supervision ('walking a different path', 'a changed interface'[1]).

A time of heightened self-awareness and peer orientation, group membership is an important concern in early adolescence. Young people seek belonging and acceptance within a peer group (Carr, 2009). This concern is thought to precede the establishment of a clear

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[1] The relevant key narrative theme to which the statement is referring is shown in parentheses.

sense of individual identity. Being marked out as different during this time, through bodily changes, delayed puberty, restrictions in participation, and medical interventions was one of the experiences captured by the theme of walking a different path. Participants narrated experiences of feeling different, left out, and misunderstood. This suggests for young people with CI there are social consequences for not following normative social rules (Olsson, Lyon, Hornell, Ivarsson & Sydner, 2009).

The management of CI whilst of paramount importance to well-being can conflict with adolescent strivings (Williams, Holmbeck & Greenley, 2002; Yeo and Sawyer, 2005). This was evident in several narratives; Elizabeth participated in a paintballing activity and suffered the follow day; Oliver stopped taking his medication as it got in the way of his activities. Participants narrated contradiction between establishing a sense of independence and autonomy, key developmental issues in adolescence and a necessity for dependence, reminiscent of childhood. Parents and family members were considered important for information provision, guidance, and emotional support. They were also perceived as restrictive, over-protective or cautious.

We are reminded of Vygotsky's concept of scaffolding (Vygotsky, 1978) whereby a child is guided by an adult or in collaboration with more capable peers to reach a higher developmental level. Within the theme of a fluid relationship, participants narrated change over time in their appraisal of their illness, a development of interdependence in their personal relationships and increasing self-awareness and regulation. Similarly, for some participants, receiving a diagnosis and living with CI in adolescence appeared to facilitate the achievement of developmental tasks such as separation, independence, self-awareness and self-management (walking a different path). Narratives acknowledged constraints but the most powerful message was of new opportunities and facilitated discovery, suggesting resilience and skilful management of the impact of illness. This echoes an emerging trend in

research acknowledging individual strengths and illness gains (Asbring, 2001; Hosek et al., 2002; Whitehead, 2006).

What is the role of adolescent-onset chronic illness in identity formation?

One of the overarching developmental issues of adolescence is the formation of identity, a sense of the self. The role of adolescent-onset CI was evident in participant narratives. Consistent with previous research (Charmaz, 1990; Mackner & Crandall, 2006; McKinney, Schiamberg & Shelton, 1998), the role of social relationships was endorsed in the stories told about interactions with others. Fragile friendships, worries about the perceptions of others and validation through social endorsement (a changed interface) were some of the powerful shared narratives explored.

Identity has been conceptualised as a psychosocial phenomenon (Erikson, 1968; McAdams, 2001); in order to form an identity young people must develop a sense of uniqueness, a consistency of self and achieve psychosocial reciprocity between self-perceptions and those of others. The necessity to hold in mind conflicting aspects of the self, and preserve a public face to minimise social judgements (tolerating contradiction) made it difficult for participants to develop a coherent and consistent sense of identity. Narratives of the role of others' appraisals (a changed interface) appeared to capture inconsistencies between such appraisals and the developing internal view of the self that participants held. Melissa spoke about feeling vulnerable when disclosing her CI to others, in contrast to her self-image of being confident, loud and energetic.

Mullins, Wolfe-Christensen, & Pai et al. (2007) speculated that as adolescents seek autonomy and independence, parents are less likely to engage in overt overprotection yet may still perceive their child as vulnerable. This perception may be communicated implicitly or explicitly to the young person leading to ambivalence and uncertainty about their health and capabilities (Mullins et al., 2007; Olsson et al, 2009). The impact of parental appraisals are

unique to the adolescent experience given that it at this time that issues of autonomy and self-awareness are most salient.

How do adolescents incorporate their diagnosis into their identity?

The permanence of CI was explored with some difficulty by participants. In the process of identity exploration young people are thought to develop identifications with others, ideologies and beliefs. Those that appear to be congruent with the emerging sense of self are retained and incorporated into the identity (Erikson, 1959). Those that appear incongruent are discarded. The same process of incorporation cannot be followed within the context of a CI. Melissa spoke about her difficulties in viewing her illness as a part of her, as it was unwanted and imposed. This was not a static concept and changed over time.

A particular nuance of the accounts was of how participants accepted and tolerated CI as part of a bigger identity. Within the theme of a fluid relationship, activities providing alternative sources of information for identity (e.g. band membership, training in sports, and caring for others) communicated efforts to maintain other separate parts to their identity where they felt able to forget about their illness. All participants narrated this need to accept and adapt to illness in order to move forward. This stoicism can be likened to the developmental process of exploring and seeking sources of information to establish a sense of identity.

Incorporation differed according to participants' age-related developmental level. Participants who were older at diagnosis (e.g. Oliver and Elena) demonstrated more cognitive awareness and incorporation (Adamson & Lyxell, 1996). Those who were younger at diagnosis narrated more difficulties and were occupied with ideas of group membership, acceptance and sameness (Clare and George). Similarly the impact of time was evident, with those participants recently diagnosed narrating difficulties in incorporating CI and of idealising their pre-identity self (Melissa). For Elizabeth and Alexander, the trajectory of

incorporating and acceptance was narrated. They drew on past experiences and knowledge to reduce uncertainty surrounding their CI.

Participants drew on dominant discourses of health and illness (Murray, 2000) and used them to develop their own identity narratives in the context of CI. Ricoeur reminds us that "we learn to become the narrator of our own story without completely becoming the author of our life" (Ricoeur, 1991, p437). Whilst no participant explicitly acknowledged dominant social discourses surrounding adolescence, they all spoke of what they perceived to be normative expectations and experiences. Narratives contained expressions of "missing out", "the right to have fun", and of "only having this time once".

Implications

The study builds on previous work exploring experiences of young people with chronic illness (e.g. Dovey-Pearce, Doherty & May, 2007; Taylor, Gibson & Franck, 2008; Woodgate, 1998). Limitations of qualitative research, such as limited generalisability apply. The small sample size and methodology employed resulted in a co-construction between the researcher and the participants and as such is but one interpretation made at a particular point in time (Riessman, 1993). Efforts to increase trustworthiness of the study, such as the reflective journal and examples of the analysis, offer the reader an account of the analysis process and may increase confidence in the findings.

The narrative themes offer a starting point for further enquiry in this under-researched area. It is important to continue to explore experiences of young people with CI. The dominant view of adolescence as a difficult and challenging time and of young people with CI experiencing significant suffering is challenged here. By sharing their experiences, young people with chronic illness can influence and challenge dominant views (Murray, 2000). Longitudinal studies would explore processes of identity formation over time and

comparative studies with healthy peers exploring the extent of the impact of CI may be useful to investigate differences.

Clinically, understanding developmental processes that young people negotiate during adolescence and incorporating this into clinical practice is vital. Opportunities for young people with adolescent-onset CI to explore identity alternatives are important. Time and space to reflect on their struggles and difficult experiences is needed. It may be that the process of struggling facilitates growth.

Conclusion

Adolescent-onset CI was found to have significant, though not exclusively negative, impacts on developmental tasks. Identity formation was influenced at the personal level through interactions with others, feelings of control and new perspectives illuminated through diagnosis. Dominant social narratives surrounding health and illness also played an important role in identity formation. Various positions emerged in the incorporation of CI into identity; the overwhelming sense is that young people endeavour to accept their illness and experience adolescence regardless. The findings are supported by wider theoretical literature in health and developmental psychology. It is hoped they will inspire and challenge professionals working with this group of young people.

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SARAH L. WICKS, BSc HONS

**A narrative exploration of the impact of adolescent-onset
chronic illness on identity formation in young people**

SECTION C: CRITICAL APPRAISAL

Word Count:1993

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

JULY 2011

DEPARTMENT OF APPLIED PSYCHOLOGY
CANTERBURY CHRIST CHURCH UNIVERSITY

Contents Section C: Critical Appraisal

Summary of research

This study aimed to explore the impact of adolescent-onset chronic illness (CI) on identity formation in young people. A narrative approach was used to identify the impact of diagnosis at a time when issues of identity were most salient. This paper will begin by exploring the learning that has occurred as a result of completing this study, first in terms of research skills and secondly concerning the research process. Clinical implications of the study will be explored and suggestions for the direction of future research will be made.

Reflections on research skills

This section describes the research skills and abilities that have been learnt as a result of undertaking this project, and identifies further learning needs.

The narrative analysis approach

Given my focus on adolescence and the process of identity formation capturing transformation over time, narrative analysis was considered to be the most appropriate methodological approach. Exploring other qualitative methods allowed me to gain skills in selecting the most appropriate methodologies for study aims. Grounded theory would have been appropriate to study the experience of having a CI but not how young people storied their experiences in terms of how it shaped their identity (Chamberlain, Stephens & Lyons, 1997). Discourse analysis may have been appropriate in a wider study of social discourses but would not address questions about identity and the reflection of personal narratives on an individual level (Willig, 2001).

The skills needed to interview young people to encourage the telling of stories for research purposes felt very different to the skills used in clinical interviews for

which I have been trained. I negotiated the dilemma between bringing a series of questions or topics that I wanted to explore and allowing participants to shape the agenda of the interview (Murray, 2003). The openness of the narrative interview may have alienated these participants, inviting suspicion and anxiety, prompting brief responses rather than explorations of experience. I made efforts to consider the developmental stage of the participants and their abilities to reflect and make sense of their experiences. A semi-structured interview schedule was used to offer some guidance and prompts used where necessary to encourage the telling of stories. Murray (2003) suggests that the resistance of participants to tell their story and to feel that it is worthy of telling, may tax the patience of the naive researcher. I certainly identified with this, feeling more connected to some participants than to others.

During the analysis I became aware of stories that had been started but not completed. I am interested to explore further the theoretical division between what have been termed the "small" and "big stories" (Squire, Andrews & Tamboukou, 2008, p7). Small stories research is argued to prioritise event over experience and prefer socially-orientated narratives. Big story researchers prefer the experiential richness of individual focused reflections. I would be keen to explore the relative merit of each and look for ways in which they may be combined or attended too simultaneously.

Quality assurance

Considering the traditional notions of reliability and validity is questioned in narrative research as they assume there is a realist truth to be discovered (Reissman, 1993). Exploration was undertaken to understand how these concepts can be incorporated into narrative research. Research findings are considered reliable if they are consistent across different occasions. Narrative analysis assumes that the stories

people tell are co-constructed by the researcher (Burck, 2005) and dependent on context, meaning that the findings may not replicate easily (Willig, 2001). Validity in narrative analysis refers to the trustworthiness and believability of a claim (Polkinghorne, 2007). A number of methods were explored to increase the trustworthiness of the findings such as the reflective diary and considerations of coherence within participant's narratives. The possibility of alternative readings and consensual validation was explored in supervision. The analysis may have benefitted from member checks, where the interpretation is taken back to participants for verification of adequate representations (Reismann, 1993). A future learning need would be to explore the impact of respondent validation and the dilemma of disagreement should it arise.

Involving service-users in the development of the study by piloting information sheets and the interview schedule provided valuable feedback regarding my use of language and terminology and may have increased the potential acceptability of the study to young people, increasing participation rates.

Reflections on the research process

This section explores reflections on the research process and consideration of any changes that could be employed if this project was to be repeated.

Personal reflections

Due to narrative analysis having no specific and unified method (Andrews, Squire & Tamboukou, 2008; Dallos & Vetere, 2005; Reismann, 1993), I experienced anxiety and felt overwhelmed by the narrative literature that I read. I wanted to both select a structured and clear analysis method for the study to ensure I was doing it 'right' but also wanted to accurately represent the stories that I was hearing. I took

salvage in advice from my supervisors to draw out only the key messages and to leave others out. I was reminded frequently throughout the process of Mason's (1993) concept of 'safe uncertainty'. My default position is to seek 'safe certainty' so this research process introduced me to the challenges and anxieties of 'not knowing'. I understood this as possibly similar to the uncertainty voiced by participants about their experience of living with CI; their concept of safety and of certainty had been lost.

As narratives are co-constructed between the researcher and the participants the identification, acknowledgement and bracketing of personal biases and assumptions is paramount (Ahern, 1999). It was important for me to own my perspective to minimise its impacts on the analysis. Despite these efforts, the analysis inevitably becomes filtered through the lens of my own perspective. Given that I live with a diagnosis of chronic illness, diagnosed in early childhood, I considered how my experiences would impact on my interpretation of the stories I heard. A pre-research reflective interview was conducted with a fellow trainee and included as an appendix in an attempt to provide an account of decision making and interpretations relating to the data collected.

Limitations of current study

The challenges of narrative interviewing discussed earlier to encourage the telling of stories within an open interview were considered alongside the developmental stage of the participants. Adolescent interviewees present "unique opportunities and dilemmas" (Elder & Fingerson, 2001, p.181) for the researcher. Attempts were made to structure the interview accordingly; beginning with unstructured questions, using participants own language in reflections and paraphrasing to encourage elaboration and creating a natural context by interviewing

in an environment with which participants were familiar. It felt as though attempts to address flaws in the research process introduced their own complications. I had to use my judgement to make the best decisions I could for this particular study and accept that there were no perfect solutions, just solutions that were felt to be good enough. I would no doubt engage in a similar process if this study was to be repeated.

The current study is limited by the use of single interviews to collect narrative accounts from adolescent participants. In retrospect it may have been helpful to have met with the young people on more than one occasion to establish rapport, to encourage the telling of more stories and to explore some of the stories in more depth following an initial analysis. This could have been met with resistance and reduced levels of participation due to increased demands for time and effort. I could also have considered using focus groups to facilitate the sharing of stories with peers in a similar situation. The challenge is that given adolescents' strong desire to be accepted by peers, and worries over how they are perceived, expression of certain narratives may have been inhibited (Ovretveit, 1998).

Reflections on consequences for clinical practice

Reflections on the potential clinical implications of having conducted this research are discussed according to key areas of clinical practice. Qualitative research is often criticised for having limited generalisability to a wider group. Although an in depth analysis of a small number of individual experiences, the findings of this study can open the mind to possibilities which may be helpful in clinical practice.

Working with young people

The view of young people with CI experiencing significant difficulties during adolescence and in processes of identity formation is challenged by the findings of

this study. The findings add to a building literature on the resiliencies of young people. Working with young people to support them to successively manage the impacts of their illness on their activities would foster the strength and adaptability that they showed here.

Clinically, understanding developmental processes that young people negotiate during adolescence and incorporating this into clinical practice is vital. The present study can aid clinicians in negotiating the dilemmas of working with young people who are juxtaposition between childhood and adulthood. Clinicians can improve interventions with adolescents by first evaluating their cognitive and psychological level of functioning in terms of capacity for self-management, responsibility and self-reflection and then applying the most developmentally appropriate interventions and expectations (Sturdevant & Spear, 2002). Deciding on how much or how little to involve parents in the care of young people is a clinical judgement that needs to be negotiated carefully during this transitional period.

Psychological impacts of medical interventions

The present study has highlighted the potential psychological impacts of medical interventions. Health psychology typically resides within a medical model approach where symptoms and medical treatment are discussed. Clinical psychologists can contribute to the management of health conditions by exploring the psychological impacts of interventions, which may in turn influence adherence. The powerful appraisals that young people made of their health conditions and treatments were voiced in this study. Participants spoke of shame, embarrassment, and disgust. Clinical psychologists can work to identify negative appraisals and therefore assess the acceptability of treatments.

Time sensitive treatments should be offered to young people at key points, for example transfer to secondary school. Training could be provided in social skills to support young people to talk about CI with peers.

Impact of dominant social narratives

An understanding of the influence of dominant social narratives on an individual's experience of health and illness is needed, be it physical or mental, acute or chronic illness. Christie and Viner (2005) bring to our attention to the fact that in adult medicine, adult clinicians converse with adult patients who may share largely similar social values and norms. In working with adolescents, clinicians need to be mindful of the challenges of communicating with young people who may not share the same understanding or possess the same cognitive abilities to make the same informed choices about their health care.

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Considerations for further research

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This final section considers future research directions in this area. Ideas are discussed in terms of the questions that future work would seek to answer and in terms of how this work could be undertaken.

By sharing their experiences, young people with CI can influence and challenge dominant views (Murray, 2000). Longitudinal studies could explore processes of identity formation over time. Future research needs to investigate a consistent age group so that findings can be more clearly assimilated in relation to this particular developmental stage. Comparative studies exploring the extent of the impact of CI may be useful to investigate differences between young people with CI and healthy peers. Difficulties in mastering the developmental tasks of adolescence may always

have been negotiated in this way for these young people. For others, difficulties may have been attributed elsewhere such as to parental relationships rather than to CI.

Research has shown that context can be either facilitating or restrictive and the construction of stories of identity depends on psychosocial reciprocity. It would be interesting to consider the systemic impact of CI on family identity. A narrative approach with family groups would enable family stories to emerge, observing the influence of dominant stories and the positioning of young people with CI within the family group.

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SECTION D: APPENDIX OF SUPPORTING MATERIAL

A thesis submitted in partial fulfilment of the requirements of
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CANTERBURY CHRIST CHURCH UNIVERSITY

Contents Section D: Appendix

Appendix 1: Literature search strategy

An electronic database search was conducted using PsychINFO (1806 to December Week 1 2010), MEDLINE (1948 to November Week 4 2010), Science Direct, EMBASE, Web of Knowledge, and Assia. Limits were placed to retrieve records in English. The following search terms were used:

1. Identity, identity formation, self, self-concept.
2. CI, chronic condition, long-term condition.
3. Adolescent, adolescence, youth, young people, young person, young adult, emerging adult.

Search terms were used together in different combinations to ensure as much work as possible could be captured. Relevant abstracts were identified and those studies considered relevant to the research were retained. Searches of these databases yielded a total of 7 empirical studies that met inclusion criteria of the use of an adolescent sample (10-20 years), with a chronic illness that is incurable, life long, requires a medical regimen and places limits on activity. If the study concerned aspects related to identity but made no reference to its contribution to identity it was excluded. Five of these articles concerned adolescents (10-19 years) and one, emerging adults (18-30 years). A further article was retained as it contained a mixture of adolescent and adult participants (13-63 years).

Additional searches were conducted in Google Scholar and articles were cross-referenced. References in identified studies were also hand-searched. This yielded a further 5 papers; 4 adolescent and 1 emerging adult. Four articles reporting identity formation in adults were retained to supplement and for comparison with the adolescent literature as they reported transition and change over time. It was thought that including exploration and integration of CI diagnosis into established identities may offer insight into the integration of CI into an emerging identity. A total of 16 empirical studies were identified for review.

A number of theoretical works were consulted to explore the context within which the research literature resides. Ten works were included that related to theoretical perspectives.

Appendix 2: NHS ethics committee and R&D approval letters

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Appendix 3: Letter of invitation to participants over 16 years

![Canterbury Christ Church University Salomons logo]

R&D project ID: 09/H0712/70
Chronic illness and identity development in young people

Dear

I am writing to ask for your help with an exciting research project we are undertaking based here at ████████████████████.

The research aims to better understand the experiences of young people who are diagnosed with a chronic health condition during adolescence. In particular, it will help us learn about some of the key issues that face young people, their varied experiences of living with a chronic condition and the effect that this has on how they see themselves.

It is hoped that the knowledge gained from this research will inform the development of future services and therefore assist young people by offering the right support at the right times.

We really hope that as many people as possible decide to take part, as larger numbers will allow us to answer our questions in more detail, and so understand young peoples' experiences better.

Enclosed with this letter, are two information sheets, a green one for you and a white one for parents if you want to share this with your parents. These information sheets tell you all you need to know about the study, what it involves and how long it will take. *We urge you to read this carefully before deciding if you want to take part or not*. **Deciding not to take part will not affect <u>your care</u> with our service in any way.**

The individuals involved in conducting the research are:
- **Sarah Wicks**, Trainee Clinical Psychologist, Department for Applied and Social Development, Canterbury Christ Church University.
- **Dr** ███████, Chartered Clinical Psychologist for ████████████████████ ████████████████████
- **Dr Paul Camic**, Clinical Research Director, Dept.of Applied and Social and Psychological Development, Canterbury Christ Church University
-

If you would like to help us by taking part in this research, or you have any questions or would like to know more about this study please contact Sarah Wicks or Dr ███████ who are overseeing this research project.

Email: ***This has been removed from the electronic copy***
Telephone: ***This has been removed from the electronic copy***

We would like to thank you in advance for your support
Yours sincerely

Named Consultant   **Sarah Wicks**
██   **Trainee Clinical Psychologist**

Supervised by:
Dr ████████
Clinical Psychologist
████████████████████████████
████████████████████ NHS Trust

Dr Paul Camic
Clinical Research Director
Dept.of Applied and Social and Psychological Development
Canterbury Christ Church University

Appendix 4: Participant information sheet for young people

R&D project ID: 09/H0712/70

Chronic illness and identity development in young people

Hello – I would like to invite you to take part in a new research study. Before you decide if you want to take part, I need to tell you about the study and how you might help us. You can talk about it with your family, friends, doctor or nurse if you want.

What is the research about?

I am interested in finding out if receiving a diagnosis of a chronic illness in adolescence such as diabetes, Irritable Bowel Syndrome, Crohn's or Juvenile Arthritis can change the way you see yourself. This is important to help us better understand the experience of young people and offer support at the right times.

Why have I been invited?

I am interested in talking to young people who are between 15 and 19 years old. You will be under the care of a medical consultant at

You need to have received your diagnosis between the ages of 13-18 years, and have had your diagnosis for between 1-4years.

Do I have to take part?

No. If you don't want to take part that's OK. It's also OK for you to decide to stop doing the research at any time. You don't even have to say why. Your decision to take part or not will not affect any of the treatment you receive.

What would I have to do?

If you decide to take part, you will meet with me so I can ask you some questions about you, your diagnosis and how you see yourself. This should take no longer than 1 hour.

What will happen to the information I give you?

The talking that we do together will be recorded to help me to remember what you say. Once the interview has been typed up, the audio recording will be deleted.

All the information you give me is private and confidential. However, some of the words you say (direct quotations) may be used in a report of this study. All of the information that would mean you could be identified will be removed.

All information about you will be kept in a password protected file at ███. No one else will be able to see or access your information. What you say during the interview will be kept in a password protected file at Salomons (Canterbury Christ Church University), at ███ and with me for 10 years. There will be no information that means you could be identified.

Who else will know that I am taking part?

You do not have to tell anyone you are taking part if you don't want to. I need to write to your consultant at ███ to inform them that you are taking part, but no-one in the service treating you will hear your responses.

The only time I would have to tell someone about what had been said during an interview was if a young person told me they were being hurt, or were going to hurt themselves. If this happened I would talk to the young person first about what was the best thing to do.

Has anyone checked the study is safe?

Before any study is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They have decided that this research is fair and safe.

What are the possible benefits of taking part?

I can't promise that this study will help you directly but the results will help to improve future care for young people living with chronic conditions.

You will be sent a summary report of the findings from the study once the study has been completed.

Your travel costs of attending the interview in ███ will be paid. We are also offering a £10 music, book or mobile phone voucher for your time in taking part in this research.

Could anything negative occur as a result of taking part?

We don't expect you will have any problems taking part. We just want to hear about your views! But if you are not happy about anything you can talk to your doctor or nurse, or your parents. You have the choice to leave the study at any time if you want to. You will also have the opportunity to be referred to the Psychology Service here at ▆▆▆, who are experienced in supporting young people with chronic illness if you think this would be useful.

If you have a complaint about the way you have been dealt with or you have a concern about any aspect of the study, you should ask to speak to the researcher overseeing the project who will do their best to answer your questions [Dr ▆▆▆▆, Clinical Psychologist, Direct Line: ▆▆▆▆▆▆). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. You can get more information about this from your clinic.

So if I do want to take part, what should I do now?

If you decide that you want to take part that's great. You can either contact me directly or you can let me know when I call you in a couple of weeks. We will need to arrange a time to meet at ▆▆▆ and will try to combine this with your usual clinic appointment. I will explain the study to you and answer any questions you might have. If you are over 16 years of age you will need to complete and sign a consent form. If you are under 16 years, you **and** your parent/guardian will need to sign the forms.

Further information and contact details
If you…

- Would like to take part
- would like general information about research or like to know more about this study

Please contact me:

Sarah Wicks
Trainee Clinical Psychologist,
Salomons, Canterbury Christ Church University
Email: *This has been removed from the electronic copy*
Telephone: *This has been removed from the electronic copy*

If you would like to discuss with someone whether or not you should participate in research generally please contact the Patient Advice and Liaison Service (PALS) on ▆▆▆▆▆▆.

Thank you for taking time to read about this study

Appendix 5: Letter of invitation to parents of participants under 16 years ██████

████ R&D project ID: 09/H0712/70
Chronic illness and identity development in young people

Dear   and

I am writing to ask for your help with an exciting research project we are undertaking based here at ███████████████.

The research aims to better understand the experiences of young people who are diagnosed with a chronic health condition during adolescence. In particular, it will help us learn about some of the key issues that face young people, their varied experiences of living with a chronic condition and the effect that this has on how they see themselves.
It is hoped that the knowledge gained from this research will inform the development of future services and therefore assist young people by offering the right support at the right times.

We really hope that as many people as possible decide to take part, as larger numbers will allow us to answer our questions in more detail, and so understand young peoples' experiences better.

Enclosed with this letter, are two information sheets, a white one (for parents) and a green one (for young people). These information sheets tell you all you need to know about the study, what it involves and how long it will take. *We urge you to read this carefully before deciding if you want to take part or not*. **Deciding not to take part will not affect your child's care with our service in any way.**

The individuals involved in conducting the research are:
- **Sarah Wicks**, Trainee Clinical Psychologist, Department for Applied and Social Development, Canterbury Christ Church University.
- **Dr** ████████, Chartered Clinical Psychologist for ████████████ ███████████████████
- **Dr Paul Camic**, Clinical Research Director, Dept.of Applied and Social and Psychological Development, Canterbury Christ Church University

If you would like to help us by taking part in this research, or you have any questions or would like to know more about this study please contact Sarah Wicks or Dr ████████ who are overseeing this research project.

Email: ***This has been removed from the electronic copy***

Telephone: ***This has been removed from the electronic copy***

We would like to thank you in advance for your support

Yours sincerely

Named Consultant   **Sarah Wicks**

████   **Trainee Clinical Psychologist**

Supervised by:

Dr ████████

Clinical Psychologist

████████████████████████████████

████████████████████ NHS Trust

Dr Paul Camic

Clinical Research Director

Dept.of Applied and Social and Psychological Development

Canterbury Christ Church University

Appendix 6: Parent information sheet

![Canterbury Christ Church University Salomons logo]

R&D project ID: 09/H0712/70
Chronic illness and identity development in young people

Please take your time to read the following information carefully.

This research project has been reviewed and approved by the NHS St Mary's Research Ethics Committee.

1. **Purpose of the study**
The research aims to better understand the issues that face young people living with chronic health conditions. The research will ask young people to talk about their experiences of receiving a diagnosis in adolescence and living with a chronic condition, such as diabetes, Irritable Bowel Syndrome, Crohn's disease or Juvenile Arthritis as well as how they see themselves. It is hoped that the knowledge gained from this research will inform the development of future services and assist young people by offering the right support at the right times.

2. **Why is my child being invited to participate?**
We are inviting young people between the ages of 15 and 19 years who are under the care of a medical consultant at ███ to be involved in the research. Your child will have received a diagnosis of medical condition between the ages of 13-18 years, and have had their diagnosis for between 1-4years.

3. **What will happen to my child?**
Your child would be asked to take part in an interviewer with a researcher, Sarah Wicks which should last no more than one hour. Interviews will be arranged before or after attending your child's regular hospital appointment.

4. **Does my child have to participate?**
Your child's participation in the research is **entirely voluntary**. They are free to decide not to take part, or to withdraw from the research at any time without having to give a reason. If they choose not to take part, or to withdraw at any time, this will in **no way** affect their future medical care.

5. **What will happen to the information given by my child?**

Interviews will be audio recorded and transcribed. Once transcribed, the audio recordings will be deleted. The interviews will be analysed by the researcher Sarah Wicks. All of the information collected in this study will be stored securely, and all names and personal information will be removed to insure the information is anonymous. Personal details that have been collected for the purposes of making contact with you and arranging an appointment to meet will be kept separately and securely, and will be destroyed at the end of the study. All information collected in interview will be kept in a password protected file at Salomons (Canterbury Christ Church University), at ▇▇ and with me (Sarah Wicks) for 10 years.

6. Who else will know that my child is taking part in the research?

Your child's medical consultant will be informed that your child is participating in the study but no-one in the service treating your child will hear their responses. You and your child are welcome to discuss this research with who ever you want, including friends, family, the doctor or clinical nurse specialist.

7. What are the benefits of taking part?

We cannot guarantee that this study will help your child directly but the results will help to improve future care for young people living with chronic conditions.

Your child's travel costs of attending the interview in ▇▇ will be paid. If your child is under 16 years old your travel costs to accompany your child will also be paid. We are offering your child a £10 music, book or mobile phone voucher for their time in taking part in this research.

8. What if there is a problem?

The questions are not intended to cause distress in anyway and we do not expect that your child will have any problems taking part. However, if your child is not happy about anything relating to the study he/she can talk to their doctor or nurse. They also have the choice to withdraw from the study at any time of they want to.

In addition, all people who decide to take part will be offered the opportunity to be referred to the psychology department here at ▇▇ if the research has raised matters that distress them.

Any complaint about the way that you or your son/daughter have been dealt with during the study or any possible harm they might suffer will be addressed. If you have a concern about any aspect of the study, you should ask to speak to the researcher overseeing the project who will do their best to answer your questions [Dr ▇▇, Clinical Psychologist, Direct Line: ▇▇). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from your clinic.

9. What happens now?

If your child would like to help us by taking part in this research, they, or you, can contact me directly or you can let me know when I contact you in a couple of week's time. We will need to arrange a time to meet at ▇▇ and will try to combine this with your child's usual clinic

appointment. I will explain the study and answer any questions they or you might have. If your child is 16 years old or over they are legally able to consent to participate and I will ask them to sign a consent form. If they are under the age of 16 years we will also require your agreement for them to participate and I will ask you to sign a consent form as well.

10. Further information and contact details
if..
- Your son/daughter would like to help us by taking part in this research
- You would like information about the research or like to know more about this study

Please contact:

Sarah Wicks
Trainee Clinical Psychologist,
Salomons, Canterbury Christ Church University
Email: *This has been removed from the electronic copy*
Telephone: *This has been removed from the electronic copy*

If you would like to discuss with someone whether or not you should participate in research generally please contact the Patient Advice and Liaison Service (PALS) on ███████████.

Appendix 7: Participant consent and assent form

![Canterbury Christ Church University – Salomons logo]

Project ID number: 09/H0712/70
Patient Identification Number for this study:

CONSENT FORM

Title of project: **The impact of a diagnosis of a chronic illness on adolescent identity development.**

Name of Principal investigator: **Sarah Wicks**

Please initial box

1. I confirm that I have read and understood the information sheet dated 27.10.09 (version 3) for the above study and have had the opportunity to ask questions.

2. I have thought about the information given about the study, and asked my parents or the researcher about any questions I have.

3. I understand that I do not have to take part in the study. I know that I can leave the study at any time, and that I do not need to give a reason why. I understand that this will not change the care I get form the doctors and nurses at the hospital, and that no-one will be angry if I change my mind.

4. I understand that my consultant will be informed that I am taking part in the study.

5. I understand that direct quotations may be used in the report for this study. These will be anonymised and identifying information removed.

6. I understand that if I become distressed or disclose information concerning thoughts of harming myself or of harm coming to me, my consultant will be informed.

7. I would like to take part in the study, but I know I can always change my mind later if I want to.

Continued on next page/

_____   _____   _____
Name of patient   Date   Signature

_____   _____   _____
Researcher (to be contacted   Date   Signature
if there are any problems)

Comments or concerns during the study
If you have any comments or concerns you may discuss these with the researcher. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, ███ ████████. Please quote the ████ project number at the top this consent form.

1 form for Patient;
1 to be kept as part of the study documentation,
1 to be kept with hospital notes

Appendix 8: Parental consent form for participants under 16 years ██████████

Canterbury Christ Church University

Salomons

██████ Project ID number:
Patient Identification Number for this study:

<u>**CONSENT FORM**</u>

Title of project: **The impact of a diagnosis of a chronic illness on adolescent identity development.**
Name of Principal investigator: **Sarah Wicks**

Please initial box

1. I confirm that I have read and understood the information sheet dated ……..
   (version ……..) for the above study and have had the opportunity to ask
   questions.

2. I confirm that I have had sufficient time to consider whether or not I want my
   child to be included in the study

3. I understand that my son/daughter's participation is voluntary and that I am
   free to withdraw at any time, without giving any reason, without my child's
   medical care or legal rights being affected

4. I understand that my child's consultant will be informed that my child is
   taking part in the study.

   I understand that direct quotations may be used in the report for this study.
5. These will be anonymised and identifying information removed.

6. I understand that if my child becomes distressed or discloses information
   concerning thoughts of harming them self or of harm coming to them, their
   consultant will be informed

7.
   I agree for my child to take part in the above study.

Continued on next page/

███ Project ID number:
Patient Identification Number for this study:

_____   _____   _____
Name of parent   Date   Signature

_____   _____   _____
Researcher (to be contacted   Date   Signature
if there are any problems)

Comments or concerns during the study
If you have any comments or concerns you may discuss these with the researcher. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, ███ ███. Please quote the ███ project number at the top this consent form.

1 form for Patient;
1 to be kept as part of the study documentation,
1 to be kept with hospital notes

Appendix 9: Copy of interview schedule

Thank you for taking part in my research. I am interested in finding out if receiving a diagnosis of a chronic illness during adolescence can change they way you see yourself. I want to ask you some questions today about yourself, your diagnosis and how you see yourself. If there are any questions you do not want to answer that is OK, Just let me know.

Section 1: Demographics
Age, Gender, Ethnicity, Religion, Occupation

Section 2: I'd like to ask you some information about yourself:
1. How would you describe yourself? What sorts of words would you use?
2. How would your friends describe you?
   Prompts: What sort of person would they say you are?
3. What kinds of things do you enjoy doing? What do you think you are good at?
   Prompts: Sports, reading, soduku, dancing
4. Is there someone famous who you really admire or would like to be like? (ideal self)
   Prompts: What is it you admire/like about them?
5. How do you imagine yourself in 10 years time?
   Prompts: What will you be doing? Where will you be living? What will your life be like?

Section 3: Now I'd like to ask some questions about your diagnosis:
1. When did (diagnosis) come into your life?
2. How did you find out? How were you told?
   Prompts: actual situation and circumstances, who explained it, where and when, what else was happening at that time?
3. What was that like for you?
4. What was the hardest thing about (diagnosis) coming into your life?
   Prompts: What helped? What made it more difficult?
5. How long has (diagnosis) been a part of your life?
6. When you think of (diagnosis) what comes to mind?
7. Was your life different before (diagnosis) came into it? Has having (diagnosis) affected the way you can live your life?
8. Has it changed the way you feel about yourself or describe yourself? If so how?
   Prompts: can you give me an example?
9. How would your friends say you've changed since you've been ill?
10. Does anyone in your family have a chronic illness? Is it the same/different?
11. Do you know anyone else who has to live with (diagnosis)? Do they think similarly or differently to you about it? Do they manage with it in a similar or different way?
12. Has having (diagnosis) changed your life? If so, how?
    Prompts: How independent do you feel?
                  Have your relationships changed? If so how? (family/friends)
                  Tell me something you used to do with you friend/s ......and now?
                  Have your aspirations/goals for the future changed? If so how?
                  Have your priorities changed since being diagnosed? If so how?

Section 4: Questions that connect identity and diagnosis:

1. Are there any aspects of how you think about yourself as a person changed? Or stayed the same?
   Prompts: Examples/stories about specific events

2. Are there good things about having (diagnosis) in your life? If so what are they?

3. How have you managed to live with the challenges that (diagnosis) puts in your life? What does this say about you as a person that you have been able to do this?

4. How have you coped with other challenges? Are you someone who copes well?
   Prompts: tell me about other situations in which you coped well/that was difficult

5. What was the hardest thing about receiving your diagnosis when you did?
   Prompts: What made it difficult? What helped?

6. What was it like for you becoming a teenager? What did being a teenager mean to you when you were 10 or 11 and before you were ill? And now?

7. Are there any ways that being a young person with a chronic illness makes you feel different from others? In what ways?]

8. Have your experiences with (diagnosis) changed over time? How?

9. How do you cope and manage living with your (diagnosis) and being a young person?
   Prompts: specific situations that have been difficult, what happened? Then what happened? Do you think it would have been different if you had not been ill or the same?

10. Do you notice the effect of (diagnosis) on your life? On being a young person?

Thank you for talking to me today and for answering my questions. Was there anything else that you wanted to say?

Do you have any questions?

How was it talking with me today?

Appendix 10: Pre-research self-reflective interview transcript

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Appendix 11: Extracts from reflective journal

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Appendix 12: Transcription agreement

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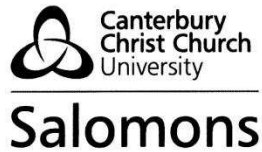
Centre for Applied Social & Psychological Development

Confidentiality Statement for Persons Undertaking Transcription of Research Project Interviews

Project title: **An exploratory study into the impact of chronic illness on identity development in adolescents**

Researcher's name: **Sarah Wicks**

The tape or tapes you are transcribing have been created as part of a research project. Tapes may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University College.

Signing this form means you agree not to disclose any information you may hear on the tape to others, and not to reveal any identifying names, place-names or other information on the tape to any person other than the researcher named above. You agree to keep the tape in a secure place where it cannot be accessed or heard by other people, and to show your transcription only to the relevant individual who is involved in the research project, i.e. the researcher named above.

You will also follow any instructions given to you by the researcher about how to disguise the names of people and places talked about on

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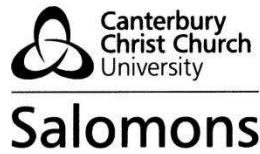
Centre for Applied Social & Psychological Development

any tapes as you transcribe them, so that the written transcript will not contain such names of people and places.

Following completion of the transcription work you will not retain any audiotapes or transcript material, in any form. You will pass all tapes back to the researcher and erase any material remaining on your computer hard drive or other electronic medium on which it has been held.

You agree that if you find that anyone speaking on a tape is known to you, you will stop transcription work on that tape immediately and pass it back to the researcher.

Declaration

I agree that:

1. I will discuss the content of the tape only with the researcher named on the previous page.
2. I will keep all tapes in a secure place where it cannot be found or heard by others.
3. I will treat the transcription of the tape as confidential information.

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4. I will agree with the researcher how to disguise names of people and places on the tapes.

5. I will not retain any material following completion of transcription.

6. If the person being interviewed on the tapes is known to me I will undertake no further transcription work on the tape and will return it to the researcher as soon as is possible.

I agree to act according to the above constraints

Your name   LESLEY ELSDON

Signature   L. A. Elsdon

Date   02/06/10

<u>Occasionally, the conversations on tapes can be distressing to hear. If you should find it upsetting, please speak to the researcher.</u>

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Appendix 13: Example interview transcript (Oliver)

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Appendix 14: Example of field notes and reflections (Elizabeth)

Description: Female, 19, Student, had to drop out of college due to illness and now restarted. Interest in helping people, participates in lots of research. Maintains contact and friendship with others on ward and staff. Spent lots of time in hospital over past 2 years. Ulcerative Colitis/Crohn's diagnosed aged 14
Field notes (Interview process, reflections, context, setting, surprises etc): Pilot interview – felt pressure to make sure interview good enough prior to interviews scheduled for following week. Had to wait an hour before hearing anything from the participant; was late due to participating on other research. Wanted boyfriend to sit in on interview with us – should I have included him more? Were there things that she did/didn't say because he was there? Did she bring him for a reason? Impression that she had told her story many times – felt practiced and responses not always related to questions. Saw CI as a good thing that had given her lots of opportunities. I was surprised at how positive she felt considering she had recently been discharged from a long hospital inpatient admission Main theme: New way of seeing things= How others could/should support her I feel guilty – she spoke about how people don't understand. I don't understand her condition but expected her to talk openly about its impact on her. I could identify with how she compared herself to others in a worse situation, similar to my own experiences. She seemed to take the fact of being different (through illness) as a reason to look/dress/think differently from her cultural peers and what was expected of her. Given her permission to embrace difference?
Reflections (following reading of transcripts and field notes, listening to audio-recordings): CI reduced her tolerance – gave her a new way of seeing what was important to her. Internalised her mothers encouraging voice to help her through difficult procedures. CI as 'hero' – " fantastic" afforded opportunities and independence, allowed her to see things differently. Arduous journey through depression, difficulties at college, but she persevered and is now in a different place with it. Adventure =- searching for a cure/treatment that works Body image as important- social messages? Idea of scaffolding – at a young age she needed parents to support her and to give her encouragement and confidence, which them allowed to be more independence and confident to take over for herself.

Appendix 15: Example of literary analysis (Oliver)

Participant: Oliver (2 years post diagnosis)

Literary Narrative Analysis

Tone	Core Narrative	Genre	Positioning	Turning point
Participant's manner of telling the story and researcher's subjective response	Summary of the story in a few words	Type of story the participant is telling	What the participant was hoping to achieve by telling the story and how they did this	
Ambivalence

Fears (future)

uplifting vs sorrow

[Control] friend/take on when he can't | Lines 146 – 148

"Right now I'm doing alright. I'm not going to let it bother me, esp at this age. I'm supposed to be having fun" | [Adventure] (present)

Risky uncertainty hazardous actions exciting experiences

[Tragedy] (future)

Main character brought to ruin – his predictions for future.

Frank's 'illness type' Quest/chaos? (present/future) | Worked incredibly hard to establish a sense of being young, having fun.

A young person who will deal with CI when he feels ready. | Stopped taking meds and suffered more disruption as symptoms worsened.

Realised he needs to take them to allow him free to have fun *now*. |

Participant Pseudonym	Jack	Clare	Elizabeth
Tone **Participant's manner of telling the story and researcher's subjective response**	Stoic	Minimising / Hard working Contradiction (fragility vs determination)	Individualist
Core Narrative **Summary of the story in a few words**	"You can't... you have to think about that (CI) as well. It's a lot of balls to juggle". (Interviewer Q) How do you manage that? "Drop the other balls". (lines 358-360)	"Em, I think as I got older the crohn's has become easier to be with (pause) but... everytime I forget, it (crohn's) always kind of nudges me that it is still there. It won't go away" (lines 308-316)	"athough there are horrendous sides to it, I have done so many things I probably would never have done in my life..../.... I think it just gave me my independence". (lines 166)
Genre **Type of story the participant is telling**	Matter of fact Real life **Stoic acceptance**	**Epic** Struggle Effort Battle	**Epic** Centered on heroic characters, captures impressive struggles, adventures, efforts of great scope over long periods of time
Positioning **What the participant was hoping to achieve by telling the story and how they did this**	Communicating his need to accept and manage the struggle.	Keen to deliver an explanation of her strength and hard work and effort to overcome adversity Hard work to maintain life as it was	Seeking validation of her sense of independence, individuality and strength. Post traumatic growth: New possibilities and opportunities for growth.
Turning point	Once condition became controlled by medication, impact on life was minimal "...it sort of ruled me, because I was ill and nobody was... I wasn't being helped with it. But now I suppose the medication works. Now I can be myself" (196-197)		Hospitalised and needing people to put her first Importance of focussing on positives and gains rather than loses

Participant Pseudonym	Alexander	George	Elena
Tone **Participant's manner of telling the story and researcher's subjective response**	Rehearsed	Minimising	Adaptable
Core Narrative **Summary of the story in a few words**	" I quite like that I've got it to be honest... I wouldn't have had this life experience I've had now. So I wouldn't trade that life for what I have now" (lines 206-209)	"Er I don't know, I just like things to be normal I guess. I like things to go on normally, I like people not to make a fuss. I don't like to be centre of attention. I like things to not be such a big deal. I get into a pattern I stick to it I guess" (lines 296-300	"Yeah, I had to learn that I can't choose...I just had to accept it is what it is and just kind of deal with it rather than kind of putting it off" (lines 370-372)
Genre **Type of story the participant is telling**	**Melodrama** Exaggerated plots and characters in order to appeal to emotions	**Journey**	**Journey**
Positioning **What the participant was hoping to achieve by telling the story and how they did this**	Resolving conflicts regarding feeling a success and welcoming the biographic disruption.	Establishing how 'normal' he was.	Explaining her journey of understanding how to live with and make compromises rather than trying to fit it around her life.
Turning point	Successful treatment " I've almost got.. I mean not officially but I feel like I no longer have it and obviously I do get the occasional flare up...... but apart from that I don't really have it" (lines 219-221)	Understanding helped "Now I'm pretty clear about what is going to happen" (lines 264-265)	Accepting longer term implications "I got quite impatient and I wanted it to go away, you know very quickly.... It was a different sort of experience trying to accept it wasn't an easy fix" (lines 356 – 359)

Participant Pseudonym	Oliver	Melissa
Tone **Participant's manner of telling the story and researcher's subjective response**	Control Sameness	Burdened Ashamed
Core Narrative **Summary of the story in a few words**	"Right now I'm doing alright. I'm not going to let it bother me...especially at this age. I'm supposed to be having fun" (lines 146-148)	" It was quite hard to er accept and think about, like what had to happen and then what would happen, how it would affect me and things...because I used to go about my daily life not thinking about it." (lines 276-78)
Genre **Type of story the participant is telling**	**Adventure (present)** Risky undertaking, hazardous actions of uncertain outcome, exciting or unusual experiences **Tragedy (future)** Main character bought to ruin or suffers distressing loss as a consequence of a tragic flaw.	**Tragedy** Main character bought to ruin or suffers distressing loss as a consequence of a tragic flaw. Struggle /Effort
Positioning **What the participant was hoping to achieve by telling the story and how they did this**	Worked very hard to establish his sense of being a young person who will deal with CI when he feels ready. Live alongside it; not letting it change you.	Expressing the vulnerability she attempts to hide in safe place.
Turning point	When he stopped taking meds and realised his symptoms got worse so he needed to attend to it in some way without letting it take over.	

Appendix 17: Example of structural analysis (identifying themes) for Alexander

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Appendix 18: Example of initial codes from the structural analysis

Known as part of me	Continuity/sameness	Always there
Guilt and responsibility	Physical effects	Embarrassment
Abnormal and different	Independence	Changed plans
Increased awareness	New perspective	Social comparisons
Not noticing impacts	Looking after others	New opportunities
CI ruled me	Additional activities	Perceptions of others
Fighting to overcome	Role of others (support)	Other parts of the self
Restrictions/disruptions	Understanding	Resilience
Determination	Prioritising	Vulnerable
Confidence	Control	Making sacrifices
Shame	Contradictions	Delayed
Articulating needs	Overshadowed	Changing body
Losing friends	Enduring treatments	Insecure
Excuse	Stoicism	Hiding
Knowing limits	Mindful of future	

Appendix 19: Example of final codes and themes

Struggle "with"
Struggle "against"

Power
- Sense of agency and control, expectations of others
- Knowledge, understanding, choice
- Uncertainty, future worries
- Seeking causal explanations

Denouncing personal responsibility, to protect self or driver for determination to overcome, social narrative of illness=not as good, responsibility and guilt X

X

Changed over time
understanding
relationship

Fluid relationship with CI
Permanence
- Lifelong
- Always there
- Not noticing, life is just the same
- One part of a bigger self, not overshadowed, look beyond

X It ruled me, can't live a normal life X

Function and role
- Physical effects of illness
- Social narratives (gender)

- Stoicism/dealing with/accepting
- Mindful of future
- Adapt
- Make it your priority
- Ups and downs

Work hard to fight and overcome, efforts to maintain a normal life

Social narratives
ill = not as good.

hide it

Forced requirements
- Practicalities and practical burdens
  - Additional activities, medications, appointments, complicates
- Emotional burdens
  - Feeling different, looking different, negative view of self, disgust, failure, vulnerable
- Premature sense of adulthood
  - Forced to grow up, be responsible, adult before time, asking questions to professionals, responsibility for healthcare, other people's expectation are higher.

Changing body, changing plans, new perspectives on what is important, ideologies,

different vs Same

Taking a different pathway

Contradictions in self
- Vulnerable vs energetic/loud
- Present vs future
- Well vs ill

Embracing opportunities

Post traumatic growth
- Independence, resilience, patience, control, adaptive

Changed interface with others
Chronic illness as a public matter
- Social endorsement, validating efforts, acceptance, normal
- Perceptions of others, shame, embarrassment, excuse
- Needing to rely on others

Appendix 20: NHS Ethics panel end of study declaration form

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Appendix 21: British Journal of Health Psychology - Contributor guidelines

British Journal of Health Psychology

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Edited By: Paul Bennett and Kavita Vedhara

Impact Factor: 1.485

ISI Journal Citation Reports © Ranking: 2009: 46/93 (Psychology Clinical)

Online ISSN: 2044-8287

Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

• papers reporting original empirical investigations;
• theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
• review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
• methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

• the content of the paper falls within the scope of the Journal
• the methods and/or sample size are appropriate for the questions being addressed
• research with student populations is appropriately justified
• the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via http://www.editorialmanager.com/bjhp/. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper.

5. Manuscript requirement
• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
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• In normal circumstances, effect size should be incorporated.
• Authors are requested to avoid the use of sexist language.
• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

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