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La transition des soins du milieu pédiatrique au milieu hospitalier adulte chez des adolescents transplantés rénaux et chez des adolescents diabétiques : Évaluation de l'identité et de l'autodétermination

par

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Résumé

Le pourcentage d'enfants et d'adolescents vivant avec une condition chronique qui atteint l'âge adulte a augmenté de façon significative au cours des dernières décennies grâce, notamment, aux avancées en médecine, donnant lieu à la question de transition du milieu hospitalier pédiatrique au milieu hospitalier adulte. Cette transition est décrite par plusieurs chercheurs et cliniciens comme étant un processus complexe pouvant être associé à des difficultés importantes, tel qu'un manque d'adhérence au suivi médical. Malgré les nombreux écrits sur cette problématique, peu d'études longitudinales ancrées dans un contexte théorique ont été réalisées. Le but de cette thèse est d'identifier des facteurs susceptibles de faciliter l'expérience de transition de patients atteints de diabète et de patients greffés rénaux en utilisant une méthodologie longitudinale ainsi qu'en se basant sur un contexte théorique défini et pertinent à la transition de l'adolescence à la vie adulte ainsi qu'à la prise en charge médicale. La thèse est présentée sous forme de trois articles scientifiques.

Le premier article examine le développement identitaire, une tâche centrale pendant la période de l'adolescence. Selon la théorie de l'identité d'Erikson (1963) et de Marcia (1966), une identité achevée, caractérisée par un sentiment de soi cohérent établi suite à une exploration, peut aider l'individu à naviguer les obstacles de l'âge adulte. La transition des soins du milieu hospitalier pédiatrique au milieu hospitalier adulte coïncidant avec le passage à l'âge adulte, il est important d'acquérir une bonne compréhension du développement identitaire d'adolescents atteints d'une condition chronique ainsi que du contexte dans lequel leur identité se développe. Dans le cadre de

cet article, le développement identitaire et la qualité de vie de 85 adolescents atteints de diabète de type 1 ou ayant reçu une greffe rénale ont été comparé à ceux de 90 adolescents en santé. Au plan identitaire, des analyses de variance ont démontré des différences significatives dans le développement de l'identité idéologique. Précisément, les résultats démontrent un niveau plus élevé de diffusion chez les patients ainsi qu'un niveau plus élevé de forclusion dans le groupe contrôle. En revanche, aucune différence entre les deux groupes n'a été détectée au niveau de l'identité interpersonnelle. De façon similaire, le groupe des patients et le groupe contrôle ont démontré des résultats comparables aux plans de la qualité de vie, de la perception de contrôle sur celle-ci, ainsi qu'au plan de la perception des opportunités à croître et se développer. Les résultats du développement identitaire sont discutés et mis en lien avec la qualité de vie rapportée par le groupe de patients.

Le deuxième article consiste en une recension de la littérature ayant pour buts de résumer systématiquement les études en transition basées sur la perspective des patients et d'identifier les facteurs pouvant faciliter l'expérience de transition au milieu hospitalier adulte. À l'aide de la méthodologie du méta-résumé, nous avons procédé à l'extraction, au regroupement et à l'abstraction de résultats provenant de 46 études qualitatives ou de nature descriptive portant sur la transition de patients. Les résultats ont été divisés en quatre catégories, notamment (1) les sentiments et les préoccupations des patients, (2) les recommandations apportées par les patients, (3) les résultats suite au transfert en milieu adulte et (4) l'impact des différents modes de transfert utilisés. Enfin,

les résultats de l'article sont discutés dans un cadre théorique de transition qui met l'emphase sur des conditions précises pouvant assurer une transition réussie.

Le troisième article a pour objectif d'utiliser une théorie pour étudier l'expérience de transition d'adolescents atteints d'une condition chronique. Étant donné l'importance accordée à l'environnement médical par les patients ainsi que les différences importantes qui existent entre le milieu hospitalier pédiatrique et le milieu hospitalier adulte, la théorie de l'auto-détermination a été sélectionnée. Selon cette théorie, la perception de soutien de l'autonomie de la part du personnel médical est intimement liée à une plus grande motivation et un sentiment de compétence chez les patients à l'égard de leur routine de soins, ainsi qu'à une meilleure adhérence au traitement. Guidés par cette théorie, nous avons suivi l'expérience de transition de patients atteints d'un diabète de type 1 ou de patients ayant reçu une greffe de rein 6 mois avant leur transfert (n= 85) ainsi que 6 mois (n= 49) et un an (n= 36) après leur transfert au milieu adulte. Les résultats révèlent que les patients se sentent généralement prêts à transférer. Suite au transfert, une baisse est enregistrée dans la perception du soutien de l'autonomie des patients. En revanche, un an suite au transfert, les patients rapportent un plus grand sentiment de choix ainsi que la perception d'une plus grande adaptation au milieu adulte. Enfin, les résultats démontrent qu'un plus grand sentiment de soutien de l'autonomie est associé à des niveaux plus élevés de satisfaction, de motivation, de compétence, et de perception d'adhérence au traitement. Les implications pratiques de cette étude sont soulignées.

Mots-clés : transition, milieu hospitalier pédiatrique, milieu hospitalier adulte, diabète de type 1, greffe rénale, adhérence, qualité de vie, identité, théorie de l'auto-détermination, soutien de l'autonomie.

Abstract

The percentage of children and adolescents with a chronic condition who reach adulthood has increased significantly in past decades due to improvements in medicine and has given rise to the question of transition from child-centered care (CCC) to adult-centered care (ACC). Transition of care has been described by researchers and clinicians as a complex process that can be associated with important challenges, such as a lack of adherence to treatment in ACC. Despite the numerous writings on the subject, there is a dearth of longitudinal studies based on a contextual framework. The main goal of the present thesis is to identify factors that can facilitate patients' transition experience by using a longitudinal methodology and by anchoring the research in a well-defined contextual framework. The thesis is comprised of three scientific articles.

The first article examined identity development, a central task of adolescence. Identity achievement, in contrast to identity diffusion, is characterized by a coherent sense of who one is following a period of exploration and can help navigate the challenges of adulthood. This study examined identity within a quality of life (QOL) context in 85 adolescents with a renal transplant or Type 1 diabetes in comparison to 90 healthy controls. Results revealed significant différences in ideological identity, with patients showing higher levels of diffusion and controls showing higher levels of foreclosure. The study revealed no differences with respect to interpersonal identity, QOL, perceived control over the QOL domains, and perceived opportunities for growth and development. The results of identity development are discussed and put in perspective based on patients' self-reported QOL.

The second article is a literature review that aimed to systematically summarize transition studies on patients' perspective and, based on these results, identify factors that facilitate transition to ACC. Using a metasummary methodology, we extracted, grouped, and abstracted the findings from 46 qualitative and descriptive quantitative studies involving patients before and/or after their transfer to ACC. Empirical results on transition fell into four groups: (1) patients' feelings and concerns; (2) patients' recommendations about transition; (3) outcomes after transfer; and (4) mode of transfer. Our results are discussed within a theoretical transition framework that emphasizes the importance of fulfilling conditions that can lead to a successful transition.

The main objective of the third article was to gain a better understanding of adolescent patients' transition experience from CCC to ACC in light of a pre-determined theory. Given the importance awarded by patients to their medical environment, the self-determination theory was chosen. According to the self-determination theory, patients who perceive their health care environment as autonomy supportive will feel motivated and competent to manage their condition and will show increased adherence to their treatment. We followed the transition experience of patients with Type 1 diabetes or a renal transplant 6 months before (n= 85), and 6 months (n= 49) and one year (n= 36) after their transfer to ACC. The results revealed that patients generally felt ready to transfer. Following transfer, there was a decline in patients' perception of autonomy support. In contrast, one year following transfer, patients reported a significant increase in their sense of choice and their adaptation to ACC. Higher levels of autonomy support

were also associated with feelings of satisfaction, motivation, competence and self-reported adherence. The practical relevance of this study is discussed.

Keywords : transition, child-centered care, adult-centered care, type 1 diabetes, renal transplant, adherence, quality of life, identity, self-determination theory, autonomy support.

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Liste des abbréviations

CHU : Centre hospitalier universitaire

CCC : Child-centered care

ACC : Adult-centered care

QOL : Quality of life

SDT : Self-determination theory

ESRD : End-stage renal disease

ANOVA : Analysis of variance

This work is dedicated to my parents,
for their love, strength and constant
support and to every person who has
played a role in shaping
who I am today.

In honour of all teenagers fiercely determined to know themselves.

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La réalisation de cette thèse n'aurait pas été la même, ni même possible, sans la collaboration, l'aide et le soutien d'un grand nombre de personnes que je tiens à remercier chaleureusement.

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Introduction

Introduction

Epidemiological studies have demonstrated that 1 out of 4 children and 15 to 18 million children and adolescents under the age of 17 suffer from a chronic health problem (Van Cleave, Gortmaker, & Perrin 2010 in Compas, Jaser, Dunn & Rodriguez, 2012). A chronic health condition can be defined as “a health problem that is prolonged, rarely cured, and often causes impairment in activities of daily living” (Compas et al., 2012, p. 18). Chronic conditions that, in the past, were typically fatal are now labeled ‘conditions of childhood onset’, because advances in medical technology have increased the likelihood that children with a chronic illness will live well into adolescence and adulthood (Madge & Bryon, 2002; Rosen, 1995). The increasing number of chronically ill adolescents surviving into adulthood has given rise to the challenge of developing transition care to bridge pediatric and adult health care. Transition of care has been defined as “a multi-faceted active process that attends to the medical, psychological, and educational/vocational needs of adolescents as they move from the child focused to the adult-focused health care system” (Blum et al., 1993, p. 573).

The transition from child-centered care (CCC) to adult-centered care (ACC) is much more complex than a simple transfer from one health care environment to another, since it occurs during the already challenging move to adulthood (Blum & Bearinger, 1990; Hauser & Dorn, 1999; Kelly, Kratz, Bielski, & Rinehart, 2002; Shidlow & Fiel, 1990). The transfer towards ACC is based on the expectation that adolescents will mature and become independent (Blum et al., 1993).

Transition from CCC to ACC is also complex and met with resistance from patients due to the differences that exist between the two environments of care. For instance, pediatrics is strongly family-centered and provides flexibility by involving family members in the patient’s care. Pediatricians in CCC offer both patients and their families nurturing care, keeping parents informed of their child’s condition (Madge & Bryon, 2002; Rosen, 1995). The bond that emerges between the young patient and the practitioner is often the product of years of treatment by the same medical team and the personal attention given to a small number of patients in pediatric care (Madge & Bryon, 2002). In contrast, as they transfer to adult health care, adolescent patients face the challenging task of adapting to an environment in which the medical staff expects them to be fully autonomous, able to negotiate health care services and make collaborative treatment decisions (Madge & Bryon, 2002; Rosen, 1995). The number of patients in ACC may be twenty times larger than the number of patients in pediatrics, making it difficult for healthcare providers in ACC to attend to their patients with the same nurturing care offered by pediatricians. In addition, older patients in ACC may receive greater medical attention than younger patients as the former group is likely to suffer from more pronounced medical complications (Rosen, 1995). Therefore, patients often perceive the process of transition as a life event involving the loss of respected and loved pediatric providers (Landau, 1995; Madge & Bryon, 2002; McDonagh, 2005; Rosen, 1995; Shaw, Southwood, & McDonagh, 2004).

Finally, the modes of communication differ between the two environments of care. In pediatrics, communication with the patient is generally made through the intermediary of the parents who also serve as a source of information with regards to their child's medical condition (e.g., symptoms). In contrast, practitioners in ACC settings rarely converse with the parents and generally prioritize direct communication with the patient with whom they expect to share equal responsibility of care (Rosen, 1995). Furthermore, practitioners in pediatric and adult systems communicate within their teams using interdisciplinary and multidisciplinary methods, respectively. In pediatrics, the interdisciplinary team is generally comprised of professionals from various backgrounds who continuously exchange information with one another. In contrast, the multidisciplinary approach used in ACC involves practitioners from various backgrounds who attend to the patient's needs individually without necessarily reporting their findings to the other members of the team (Rosen, 1995).

Additional challenges during the transition from CCC to ACC may stem from practitioners in both of these milieus. According to Viner (1999), because pediatricians tend to develop a longstanding emotional relationship with their patients, they are likely to have difficulty trusting their patients' independence, which can reduce the chances of a successful transition. In a comparable vein, practitioners in ACC may be less sensitive to the context in which patients continue to live during their young adulthood (for example, with their family) and may be less attuned to the multifaceted needs of adolescents and young adults who experience developmental delays (Stehl, 2005), thus further impacting transition negatively.

Aim and Impact of Transition

The specific aims of transition of care are numerous. Firstly, transition aims to provide uninterrupted, flexible, and comprehensive health care that corresponds to the patient's age and developmental stage (American Academy of Pediatrics, 2002; McDonagh, 2005). Secondly, it attempts to promote skills that will be useful in ACC, including communication, decision-making, assertiveness, self-care, self-determination, and self-advocacy, as well as a sense of control and interdependence in healthcare. Finally, transition aims to maximize life-long functioning and potential and provide support to the patient's family throughout the process (McDonagh, 2005).

Transition to ACC is not without potential negative consequences for the patients. Several researchers who have investigated the transition process of chronically ill adolescents from CCC to ACC have reported poor adjustment, as evidenced by a lack of satisfaction, a lack of adherence to medical treatment, or a combination of the two.

With respect to satisfaction, studies have reported that the transfer to ACC can be accompanied by a sense of loss regarding the close relationships developed with the pediatric staff (e.g., Dabadie, Trobadec, Heresbach et al., 2008; Kirk & Clayton, 2006). This feeling can often become exacerbated by the reality of ACC (e.g., higher number of patients), which can prevent medical personnel from providing patients with the same level of care they had received in CCC.

In addition to diminished satisfaction, adherence to self-administered treatment and to medical follow-ups have been shown to decline following transfer. Several studies have found a lack of adherence to medication in ACC (Wojciechowski, Hurtig, & Dorn, 2002). Other studies have reported a decline in attendance to medical follow-ups in ACC (e.g., Orr, Fineberg, and Gray, 1996; Koshy, Hebert, Lam et al., 2009; Sparud-Lundin, Ohrn, Danielson, et al., 2008). In one study, Watson (2000) reviewed the progress of 20 young renal transplanted patients during their transition to adult health care facilities. Within 36 months following transfer, eight out of the 20 patients lost their graft. In seven of those cases the graft failure was unexpected, and non-adherence was suspected to be the cause.

Proposed guidelines for a successful transition

Research studies in the field of transition care have been conducted with the main goal of rendering the process smoother for young patients and ensuring continuity of care in ACC. Thus far, researchers and clinicians interested in transition have used patients' experiences to develop recommendations that may facilitate future patients' transfer to ACC.

It is recommended that transition should occur within a developmental context, through a process that is in harmony with the patient's level of physical, psychological, and social development (Rosen, 2003; Viner, 1999). Transition from pediatric to ACC is often compounded by other transitions known to occur in adolescence (i.e., the move from dependence to independence and from family life to the conformity of peers). It is therefore necessary for practitioners to take heed of the developmental progress achieved by their patient and to tailor patient care accordingly (Rosen, 2004).

A debate exists as to the exact age at which transfer should take place, with suggestions ranging from 14 to 21 years (Rosen, 2004). However, several authors caution that the timing of the transfer should not be based solely on age, but on additional factors such as psychosocial functioning, independence, and general maturity (Cameron, 2001). In the same vein, Rosen (2004) notes that autonomy and independence are important assets required for several life events that overlap with the time of transition. Since each adolescent may develop the essential skills required for transition at a different age, most researchers posit that transition plans should be flexible, individualized, and preferably coincide with other life transitions such as the end of high school (Rosen, 2004; Viner, 2001). Importantly, transfer should only take place once patients are able to manage their medical condition (David, 2001) and have the necessary skills to function in the ACC environment (Royal College of Pediatrics and Child Health, 2003).

A successful transition is also dependent upon the adequacy of information exchanged between the CCC and ACC teams (American Academy of Pediatrics, 2002; Rosen, 2004; Viner, 2001). Prior to a transition, the ACC team must become acquainted with the patient’s medical and personal history, which should be summarized by the CCC team. This method of exchanging information is beneficial to the adult team as well as to the patient and parents who are more likely to feel that health care needs are being met appropriately. Additionally, the pediatric team in its entirety (i.e., doctors, social workers, and psychologists) should communicate with the team in ACC to ensure the transmission of all pertinent information in regards to the patient's medical, psychological, and social background (Rosen, 2004). Cameron (2001) suggests patients should meet the adult health care team prior to the transfer and, once in ACC, should prolong visits in CCC a small number of times to ensure the transfer takes place smoothly.

A successful transition is likely to occur in situations where the transfer is well coordinated and the family is involved. During the transition process, the parents' role changes from a position of control to one in which increasing independence is given to their child (Landau, 1995). During the planning of transition, health care providers should thus foresee potential changes this process may create in family dynamics and provide assistance and counseling to parents who have difficulty letting go of the extensive role they play in their child's health care (Rosen, 2004) or feel betrayed after years of being present for their child on a daily basis (Landau, 1995).

Gaps in the transition literature and objectives of the thesis

Researchers and clinicians in the past decades have given significant importance to the study of transition of care. The numerous writings and studies conducted in this field have been useful in understanding the definition of transition, the differences that exist between pediatric and adult centered health care settings, and the barriers to transition. The findings have also been of use in designing transition programs and in drawing lists of proposed guidelines to follow prior to and after transfer to ACC. Nevertheless, according to Rosen (2004) ‘there remains a paucity of outcome data, no long term outcome data at all and no agreement even as to which long-term outcomes ought to be studied’ (p. 125). Despite the numerous writings, studies, and clinical recommendations, there is indeed limited empirical data that document the factors that facilitate transition from CCC to ACC. More importantly, few longitudinal studies that offer a global overview of the transition process exist, thus impeding the ability to make associations between what takes place prior to the transfer and its impact on patients’ experience in ACC. Lastly, no transition study to our knowledge has used a sound theoretical framework. Notably, the use of a theoretical framework can assist in the organization of data into a coherent model, in suggesting innovative ways of understanding the issue, and in translating data into practical interventions (Gerrity, 1994).

In response to the existing limitations in the transition literature, the main goal of this thesis was to adopt a global approach that would allow for the identification of facilitative factors of transition of care at both the individual and contextual levels. More precisely, the aim was to gain a thorough understanding of the context during which transition of care takes place. To do so, an emphasis was put on using a longitudinal design along with a sound theoretical framework. The more specific goals of this thesis and the steps taken to achieve them are detailed as follows.

The first objective of the thesis was to gain an understanding of the individual context in which transition of care takes place. Given that the transfer to ACC coincides with additional major changes for adolescents (e.g., the end of high school and the move to higher education or to the workforce), it was deemed important to adopt an approach that would allow for the investigation of individual factors that can play a role in patients' transition of care. To do so, Erikson (1963) and Marcia's (1966) theory of identity development was chosen. Research has shown that the development of a healthy identity is associated with higher levels of well-being, self-esteem (e.g. Phillips & Pittman, 2007), and overall adjustment (e.g. Ferrer-Wreder, Palchuk, Poyrazli, Small, & Domitrovich, 2008). Furthermore, in the case of adolescents with a chronic illness, a healthy identity has been associated with the use of adaptive illness-specific coping strategies (Luyckx et al., 2008). Due to the importance of identity development during adolescence, we also set out to compare the identity development of adolescents with a chronic illness to that of their healthy counterparts. Furthermore, given that identity development does not take place in a vacuum and can be greatly influenced by the personal and social context in which individuals find themselves, we also investigated the quality of life of both the patients and the healthy control groups.

The second objective of the thesis was to investigate factors that can predict a smooth transfer to ACC at the broader contextual level in which the transfer takes place. This objective was completed in two separate steps. In the first step, we conducted a metasummary to provide a systematic integration of the transition literature based on studies that emphasized patients' experiences both prior to and following their transfer to ACC in order to describe the factors that facilitate the transition process. The metasummary included a total of 46 studies from which data were extracted, grouped in themes, and synthesized. Analysis of the articles allowed for the elaboration of clinical recommendations based on patients' transition experiences.

In the second step, we assessed variables at the medical context level in which patients' transition experiences took place. Given the importance patients attribute to the characteristics of the healthcare environment and its providers, patients' transition experiences were examined longitudinally in light of the self-determination theory (SDT), which puts an emphasis on the relationship between patients and healthcare providers. According to the SDT, patients who perceive their healthcare providers as autonomy supportive (e.g., as giving them choices) are more likely to feel motivated and competent with respect to their own health care and show higher levels of adherence to treatment. Given the important differences that can be observed between healthcare providers' practices in CCC and ACC, it was deemed important to assess whether changes can be observed in patients' perception of their healthcare environment as well as in the level of autonomy support they receive from healthcare providers. Furthermore, we aimed to understand the relationship between the level of perceived autonomy support and the levels of autonomous motivation, feelings of perceived competence, and adherence to treatment.

Presentation of the articles

The first article, entitled ‘Assessment of identity and quality of life in diabetic and renal transplant adolescents in comparison to healthy adolescents’, addresses the first objective of the thesis. It provides a detailed overview of Erikson (1963) and Marcia’s (1966) theory of identity and the methodology used is described. Furthermore, the article details the findings with respect to the identity development and QOL of adolescents with a chronic illness in comparison to their healthy peers. The article was published in the “Journal of Clinical Psychology in Medical Settings”.

The second and third articles address the second objective of the thesis, namely the identification of contextual variables that can help make transition of care smoother. In the second article, entitled ‘Patients’ perspective on factors that facilitate transition from child-centered to adult-centered health care: A theory-integrated metasummary of quantitative and qualitative studies’, the findings from a systematic review of the transition literature are presented in the form of factors that can impact patients’ transition experiences both prior to and following their transfer to ACC. Based on these findings, recommendations at the clinical and research levels are provided. This article was published in the ‘Journal of Adolescent Health’.

The third article, entitled ‘Transition from child-centered to adult-centered care in patients with diabetes and renal transplant: Feelings towards transfer and evolution of self-determination and adherence across the transition process’, follows in the vein of the second article and aims to assess facilitative factors by putting an emphasis on the context of the medical environment in which transition takes place. This article provides an overview of the self-determination theory, which was used to longitudinally investigate patients' transition from CCC to ACC. With respect to results, the article first describes patients' feelings and concerns regarding their transfer. The article further describes the ways in which patients' perception of autonomy support, feelings of motivation and competence towards their healthcare, and their adherence to treatment change during the transition process. Finally, the article details the ways in which different variables are related (e.g., the association between the perception of high autonomy support and patients' motivation to be responsible for their healthcare). This last article will be submitted for publication in the "Journal of Adolescent Health'.

Authors' contribution

"Assessment of identity and quality of life in diabetic and renal transplant adolescents in comparison to healthy adolescents"

The candidate executed the review of the literature, the data collection and data analysis, and wrote the article. The candidate also made the corrections suggested by the editor of '*The Journal of Clinical Psychology in Medical settings*'. Marie Achille reviewed the article and, in the light of her clinical experience and in the context of a continued supervision, suggested modifications with respect to its content and style. All coauthors reviewed the article prior to its submission to the journal.

"Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: A theory-integrated metasummary of quantitative and qualitative studies"

The candidate executed the data collection and the data analysis with the help of Moire Stevension. The candidate also made the corrections suggested by the editor of the "*Journal of Adolescent Health*". Marie Achille reviewed the article and, in the light of her clinical experience and in the context of a continued supervision, suggested modifications with respect to its content and style.

‘*Transition from child-centered to adult-centered care in patients with diabetes and renal transplant: Feelings towards transfer and evolution of self-determination and adherence across the transition process*’

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Chapitre un

Premier article

Assessment of identity and quality of life in diabetic and renal transplant adolescents in comparison to healthy adolescents

Assessment of identity and quality of life in diabetic and renal transplant adolescents in comparison to healthy adolescents

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Abstract

Identity development represents a central task of adolescence. Identity achievement is characterized by a coherent sense of who one is following a period of exploration and can help navigate the challenges of adulthood. This study examined identity within a quality of life (QOL) context in 85 adolescents with a renal transplant or with Type 1 diabetes in comparison to 90 healthy controls. Results revealed significant differences in ideological identity, with patients showing higher levels of diffusion and controls showing higher levels of foreclosure. No differences with respect to interpersonal identity, QOL, perceived control over the QOL domains, and perceived opportunities for growth and development were found. Future research should assess identity and QOL over a longer period of time to determine whether differences between chronically ill and healthy young adults can be detected.

Keywords: Adolescence, chronic illness, identity, quality of life.

Résumé

Le développement identitaire représente une tâche centrale de l'adolescence. Une identité achevée est caractérisée par un sentiment de soi cohérent établi suite à une exploration et peut aider l'individu à naviguer les obstacles de l'âge adulte. Cette étude examine le développement identitaire dans un contexte de qualité de vie de 85 adolescents greffés rénaux ou atteints d'un diabète de type 1 en comparaison à un groupe de 90 adolescents en santé. Les résultats ont révélé des différences significatives au niveau de l'identité idéologique, avec un niveau plus élevé de diffusion chez les patients ainsi qu'un niveau plus élevé de forclusion chez le groupe contrôle. Aucune différence entre les deux groupes n'a été détectée au niveau de l'identité interpersonnelle, de la qualité de vie et de la perception de contrôle sur celle-ci, ainsi qu'au plan de la perception des opportunités à croître et se développer. Des études futures devraient investiguer l'identité et la qualité de vie sur une plus longue période de temps afin de déterminer si des différences existent entre des jeunes adultes atteints d'une maladie chronique et ceux en santé.

Mots-clés : Adolescence, maladie chronique, identité, qualité de vie.

Introduction

Adolescence was once perceived as a tumultuous period, a notion that has changed over the past decades, in light of research findings showing that the majority of adolescents go through this life stage unscathed (Steinberg, 2008). Nevertheless, adolescence remains a life stage during which an individual undergoes important transitional changes at the biological, psychological, and social levels (Holmbeck, 2002). Although normative, these changes require adaptation. The presence of additional stressors, such as a chronic medical condition, is believed to exacerbate this already challenging life period (Grinyer, 2007; Seiffge-Krenke, 2001). A chronic condition can be defined as any condition that has a biological, psychological, or cognitive basis, has lasted a minimum of 12 months, and requires the affected individual to rely on compensatory assistance such as medication or a specific diet (Rew, 2005). As such, an adolescent diagnosed with a chronic condition is required to cope with both normative (i.e. identity development) and non-normative (e.g. a medical condition) tasks (Marinelli & Dell Orto, 1999; Seiffge-Krenke, 2001).

A number of authors have reflected that adolescence is “crucible for the shaping of later life” (Jessor & Jessor, 1977 in Rew, 2005, p. 53). Individuals going through adolescence are expected to acquire a number of skills that are necessary to adapt to adulthood. The successful achievement of important developmental tasks during adolescence is believed to influence one’s ability to handle the challenges that will arise in adulthood (Schulenberg, Bryant, & O’Malley, 2004). It is only in recent decades that the investigation of developmental tasks in adolescents with a chronic illness has become relevant. With significant improvements in medical technology, children and adolescents with a chronic illness are reaching adulthood in ever increasing numbers (Rosen, 1995). Approximately 98% of children with a chronic condition now reach 20 years of age (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). The adolescent with a chronic illness needs to successfully achieve the expected developmental milestones in order to adapt to the emerging role of adulthood and new research investigating normative developmental task acquisition in chronically ill adolescents is increasing (Fletcher-Johnston, Marschall, & Straatman, 2011). It is indeed important to assess whether adolescents who have been suffering from a chronic condition experience this developmental period in a way that is similar to their healthy counterparts.

Contextual Framework

Research has shown an impact of chronic illness on the psychological and emotional well-being of children and adolescents who, in comparison to healthy counterparts, are at greater risk for adjustment problems that may persist into adulthood (Wallander & Varni, 1998; Williams et al., 2002). The course of normal psychosocial development can be discussed in light of theories developed by Havighurst (1972) and Erikson (1963), whose work was applied by Marcia (1966).

Havighurst's (1972) theory of development is based on age-related developmental tasks, which arise at a specific period in an individual's life and must be successfully achieved for the individual to be able to accomplish subsequent tasks.

During adolescence, Havighurst mentions that the youth has to 1) accept his/her body; 2) adopt a masculine or feminine social role; 3) form mature relationships with peers; 4) prepare for an occupation; 5) prepare for a mature romantic relationship; 6) achieve emotional independence from parents; 7) establish values and an ethical system to live by; and 8) strive for social responsibility. Havighurst's work is unique since it integrates challenges from physical development, personality and identity, and societal expectations and is therefore relevant when attempting to gain a full understanding of development in adolescents with a chronic illness (Seiffge-Krenke 1998; Williams-Cato, 2003).

Many researchers and clinicians consider the central task of adolescence to be identity formation, well delineated by Erikson's theory of identity development (1959, 1963, 1968). His theory describes eight stages, each characterized by a conflict that must be resolved at a specific stage of life (Kroger, 2007). The successful resolution of each conflict is dependent upon the resolution of preceding ones. Mastery of Erikson's fifth developmental stage, identity achievement versus identity diffusion, can have a positive impact in adult life (Kroger, 2007). Although Erikson's theory is well known, demonstrates logical adequacy, and shows cross-cultural consistency, it has limitations in its differentiation between the concepts of identity diffusion and identity achievement, making it difficult to test (Rew, 2005).

James Marcia (1966) added practicality to Erikson's theory by developing the most commonly used paradigm for research on identity formation (Grotevant, Thorbecke, & Meyer, 1982; Rew, 2005; Steinberg, 2008). According to Marcia (1966), adolescence is a period during which the individual experiences a *crisis* that is resolved by making *commitments* concerning the future in the domains of occupation, religion, and ideology. Grotevant and colleagues (1982) subsequently extended Marcia's work by adding the domains of interpersonal relationships. Two core variables, namely the "crisis" or exploration of identity alternatives and the commitment to choices, allow for the classification of individuals into one of four identity statuses: diffused, foreclosed, moratorium, and achieved. While an achieved identity is characterized by a coherent sense of self following a period of personal exploration and commitment, the diffused identity status reflects a lack in both exploration and commitment. The foreclosed identity status is found in individuals who have strong levels of commitment but who did not make those commitments based on their individual exploration but rather based on choices and values instilled by others (e.g., their parents). The moratorium status reflects an individual's strong sense of exploration and is characterized by low levels of commitment. Individuals in this identity stage are in the midst of exploring and experimenting the various options they have (Marcia, 1966; Steinberg, 2008). Prior studies on adolescent identity development suggest that an individual's identity status is strongly related to variables such as well-being and self-esteem (e.g., Phillips & Pittman, 2007), and adolescent adjustment (e.g., Ferrer-Wreder, Palchuk, Poyrazli, Small, & Domitrovich, 2008), with diffused individuals showing lower levels of well-being and self-esteem and poorer developmental outcomes (Phillips & Pittman, 2007).

Identity development does not take place in a vacuum and can be greatly influenced by the personal and social context in which individuals find themselves. Kunnen and Bosma (2006) refer to identity development as a relational and dynamic process, adding that the person and the context in which they find themselves mutually impact one another. Similarly, Steinberg (2008) highlights the importance of the social context in which adolescents develop, explaining that such a context determines the nature of the self-definition search the individual will undergo. In the case of a chronic illness, it is important to assess the adolescent's satisfaction in the various areas of their life as well as in their overall QOL in order to gain a better understanding of the context in which identity development takes place.

In the past decades, research has shown that adolescents with a chronic illness are at risk for delayed psychosocial development and identity. It has been speculated that factors such as difficulty gaining independence, absenteeism from school, and delayed social maturation may affect the acquisition of developmental tasks (Boice, 1998; Williams-Cato, 2003). As well, the literature has indicated that ego development in patients with diabetes (Hauser et al., 1992) and cancer (Gavaghan & Roach, 1987) is lower than for their healthy peers.

In recent years, a small body of research has specifically looked at identity development in adolescents with a chronic illness. Madan-Swain and colleagues (2000) investigated identity development in adolescent survivors of childhood cancer in comparison to a group of healthy adolescents. Cancer survivors showed higher levels of foreclosure in comparison to their healthy counterparts. The authors hypothesized that a foreclosed identity status could serve as a protective factor by helping the survivors cope with their previous illness experience (Madan-Swain et al., 2000). More recently, Luyckx et al. (2008) examined identity development along with coping and adjustment in emerging adults with diabetes. Interestingly, they found that patients did not differ from the healthy group, suggesting that patients with diabetes are able to adapt to their illness and follow a normal psychosocial development. In addition to these findings, the same study revealed that the development of a healthy identity, in contrast to a diffused identity, was associated with using adaptive illness-specific coping strategies in the diabetic group, lending support to the importance of a healthy identity development in chronically ill youth (Luyckx et al., 2008).

Objectives of the study. While the previously mentioned studies are informative with regards to identity development in adolescents with a chronic illness, there continues to be a lack of empirical research in this domain. According to Luyckx et al. (2008), research on identity development in youth with chronic illnesses should be pursued using a developmental perspective. In the same vein, recommendations have been made to adopt a developmental perspective to the study of youth with chronic conditions, given that “health and illness occur within a changing developmental context” (Holmbeck, 2002; p. 410).

Given the discrepancy between the aforementioned findings, our approach was exploratory. The first goal of this study was to assess the identity development of teenagers diagnosed with either Type 1 diabetes or with a renal transplantation and conduct comparisons between this sample and a sample of healthy teenagers. Secondly, we wanted to assess whether differences exist between chronically ill adolescents and healthy adolescents with regards to the importance they place on various domains of their life as well as their self-reported QOL in those same domains. Similar to other studies (e.g. Meuleners, Lee, & Binns, 2001), we adopted a non-categorical approach to chronic illnesses, which acknowledges the commonalities that exist between chronic illnesses despite their differences (Perrin, Newacheck, Pless et al., 1993; Pless & Pinkerton, 1975). Although patients with Type 1 diabetes and renal transplant have different forms of treatment, they share important similarities, namely the fact that both chronic illnesses affect patients on a daily basis and require a strict medical regimen. For instance, both groups of patients partake in daily monitoring and medication taking, as well as clinic visits approximately every three months.

Method

Procedure

The population of patients with diabetes or a renal transplant was recruited in the context of a broader study on transition from pediatric health care to adult-centered health care. Patients were first informed of the study by their doctor or nurse during their visit to the nephrology or diabetes clinic. If they expressed interest in the study, patients completed a consent form allowing the principal investigator (TL) to meet with them at the clinic or to contact them at a later time. Patients were then met or contacted by phone and, if interested in participating, were given or sent a questionnaire. When the completed questionnaire was returned, the principal investigator mailed each participant a thank you note and a ten-dollar compensation.

A control group was recruited from three post-secondary institutions in Montreal. The principal investigator and a research assistant advertised the study at the beginning or at the end of different classes. Students who accepted to take part in the study received a consent form and a questionnaire to complete at home. The principal investigator and the research assistant returned the following week to collect the questionnaires and give each participant a ten-dollar compensation. The study received ethics review board approval at all institutions where recruitment took place.

Participants

Inclusion criteria for the patient group were: 1) being 17 years old or older; 2) having a diagnosis of Type 1 diabetes or a renal transplant; and 3) having an approximate date of transfer to adult-centered health care. Of the 107 patients who agreed to participate, 85 (79%) returned the questionnaire. Common reasons for withdrawing included lack of time or interest, or patients feeling tired of participating in studies pertaining to their medical condition. For the control group, adolescents had to: 1) be 17 years or older; 2) be healthy (i.e. no chronic condition); and 3) attend a post-secondary institution. The exclusion criteria of no chronic condition was explained during recruitment and was later verified in the demographic questionnaire. A total of 90 students were recruited.

Measures

Demographic questionnaire. The questions included pertained to current status, educational background, health history (i.e., presence of a medical condition, year of diagnosis, medication), current family and living situation, as well as open-ended questions on whether important life changes had taken place in the past year.

The Extended Objective Measure of Ego Identity Status (EOMEIS-2; Bennion & Adams, 1986; French version by Gohier, Chevrier, & Anadon, 2007 and Herry, Robichaud, & Boyer, 1993). This 64-item questionnaire allows for the classification of individuals into one of four identity categories: diffused, foreclosed, moratorium and achieved, for both the interpersonal (i.e., friendship, dating, gender roles, and recreational activities) and the ideological domains (i.e. occupation, religion, politics, and lifestyle). There are 16 items for each of the four identity categories, which participants are asked to rate on a 6-point Likert-type scale (1= strongly disagree to 6= strongly agree). Both continuous and categorical interpretations of the data are possible. In order to classify each individual in a specific ego identity status, we followed the guidelines proposed by Adams et al. (1998). Raw scores were first calculated for each of the subscales and means were computed from these scores. The classification of an individual is achieved by comparing their raw score to the cutoff point of each subscale. Individuals who score above the cutoff point in a single subscale are categorized in a pure ego status identity (achieved, moratorium, foreclosed, or diffused) while those who score above the cutoff points in two subscales are considered transitional and are categorized in the ego status that is less advanced. Finally, those who score above the cutoff points in three or more subscales are called low-profile moratoriums. In order to maximize the classification percentage in a pure identity status, we followed the recommendations by Jones et al. (1994) and used a cutoff of half a standard deviation above the mean.

The EOMEIS-2 has been used in both longitudinal and cross-sectional studies (Adams, 1998). It shows moderate to good reliability and validity. For each of the four categories, cronbach alphas have ranged from .53 to .75 for the ideological subscales and from .52 to .80 for interpersonal subscales (Bennion & Adams, 1986; Bennion, 1988). Reliability in our sample ranged from .52 to .78. These values are similar to those found in previous studies.

Quality of Life Profile Adolescent Version (QOLPAV) (Raphael, Rukholm, Brown, Hill-Bailey, & Donato, 1996). This questionnaire measures QOL in adolescents. It was developed through interviews conducted with adolescents and counselors and through the integration of theoretical models such as Erikson's theory of identity (1968) and Havighurst's theory of developmental tasks (1953). The questionnaire contains 54 items equally divided in three domains, being, belonging, and becoming, and each domain is further divided into three sub-domains. The being domain explores adolescents' perception of who they are by asking questions pertaining to their self-esteem, self-concept, and spirituality. The belonging domain explores adolescents' feelings of belonging to their environment in three areas, physical, social, and community. Physical belonging refers to adolescents' connection to their home, school, neighborhood and community while social belonging refers to adolescents' connection to social environments such as family, close friends and community. Finally, community belonging refers to the individual's access and involvement in social services, recreational programs, and community activities. The final domain, becoming, pertains to adolescents' achievement of goals and aspirations in the practical (e.g., work, school, volunteer activities), leisure (e.g., activities performed for pleasure and relaxation), and growth (i.e., improving skills and knowledge, adaptation to change) sub-domains. For each item in the questionnaire, respondents are asked to rate individual importance and satisfaction on a five-point Likert scale (1= not at all, 5= extremely). Finally, 18 additional items are included and allow for the investigation of adolescents' perception of the amount of control and opportunities they have over the areas mentioned above.

Psychometric properties of the QOLPAV suggest that this questionnaire has good internal reliability, with a Cronbach alpha above .80, and good validity (Raphael et al., 1996). A professional translator with experience in the field of psychology translated the questionnaire. The reliability of the measure in our sample ranged from .60 to .93.

Scoring the QOLPAV. We used the guidelines provided by Rafael et al. (1996) to obtain participants' global QOL scores. QOL is obtained by looking at the importance and satisfaction the adolescent gives to each item. Means are calculated for each of the three sub-domains for the being, belonging, and becoming categories. Following that step, the three means are averaged in order to obtain the global QOL score. Scores can range from a low of -3.33 where the individual expresses extreme importance but complete lack of satisfaction to a high of +3.33 where both high importance and high satisfaction are found. An overall QOL score of 1.50 or higher is considered very good and a score of .51 to 1.50 suggests an acceptable situation. Furthermore, scores ranging between -.50 to .50 indicate an adequate situation, while scores from -.51 to -1.50 are problematic. Scores less than -1.50 are considered very problematic.

Statistical Analyses

Data was analyzed using the Statistical Package for the Social Sciences (SPSS) version 17.0. Demographic variables were analyzed using a combination of t-tests for continuous variables and chi-square analyses for categorical variables. Identity development was first analyzed as a continuous variable. A 2 (male vs. female) by 2 (patients vs. controls) analysis of variance with Bonferroni correction was conducted on participants' level of identity development for each of the four identity states in the ideological and interpersonal domains (diffused, foreclosed, moratorium, achieved). Furthermore, chi-square analyses were used to assess the distribution of patients and healthy controls across the different identity categories at both the ideological and interpersonal levels. With respect to QOL, we first assessed whether differences could be found in the importance awarded by patients and healthy controls to each of the subdomains by means of t-tests. To investigate whether differences could be found between the two groups, we entered the score of each of the nine subdomains, overall QOL, perceived opportunities and perceived control in a series of t-tests with Bonferroni corrections. Lastly, we conducted chi-square analyses to assess the distribution of patients across the different categories of QOL.

Results

Participants' Characteristics

The final sample consisted of 85 patients (males= 37; females= 48) ranging in age from 17.49 years to 22.15 years and 90 controls (males= 38; females= 52) ranging in age from 17.00 to 20.79 years. The patient group included 54 diabetic patients and 31 renal transplant patients. Within the patient group, we found a significant difference in age with renal transplant patients being older (*M* age= 19.48) than diabetic patients (*M* age= 18.03) (*t* (83)= 9.96, $p < .001$). Similarly, a significant difference was found with respect to the age of diagnosis with diabetic patients having been diagnosed at a later age (*M*= 9.62, *SD*= 4.16) in comparison to renal transplant patients (*M*= 5.80; *SD*= 5.47) (*t* (83)= 3.64, $p < .001$) and with respect to the time elapsed since the diagnosis (diabetes: *M*= 8.41 years, *SD*= 4.22; renal transplant: *M*= 13.69, *SD*= 5.66) (*t* (83)= 7.39, *p*= .01). No significant differences were found in the gender distribution, level of education, parents' marital status and level of education, and the presence of siblings between the two groups of patients. Lastly, we did find that significantly more patients with a renal transplant (*n*= 7) did not live with their parents in comparison to patients with diabetes (*n*= 3) ($\chi^2 = 5.50$, *p*= .02)

Analyses between the patient and healthy groups showed no significant difference with respect to the distribution of gender (χ^2 (1, 175)= .031, *p*= .861). Furthermore, we found that patients had a statistically significant higher age (*M*= 18.56, *SD*= 0.95) in comparison to the healthy group (*M*= 18.29, *SD*= 0.81) (*t* (173)= 2.03, *p*= .04). The majority of participants reported being full-time students only or being full-time students while holding a part-time job. However, we found the distribution for the level of education to be unequal between the two groups. In comparison to healthy controls who were all attending a post-secondary institution, the majority of patients were in a post-secondary institution (*n*= 52) while some were in University (*n*= 3), in their last year of high-school (*n*= 18), or in the 10th grade or less (*n*= 11). No significant differences were found with regard to living arrangements, cultural background, the presence of siblings, and parents' marital status. Demographic information for the two groups is presented in Table I.

Identity as a Continuous Variable

In the ideological domain, analyses revealed that patients and healthy adolescents differed on the diffused status (F (1, 170)= 4,53, p= .035, η^2 = .026), with the former group endorsing significantly higher levels of diffusion (M= 28.19, SD= 6.74). In contrast to patients, healthy adolescents reported significantly higher levels of ideological foreclosure, (F (1, 169)= 5,24, p= .023, η^2= .03; M= 21.00, SD= 7.27). No significant differences were found in the levels of ideological moratorium and achieved statuses.

Subsequently, analyses of the interpersonal domain revealed a significant difference in group membership for interpersonal foreclosure (F (1, 170) = 4.96, p= .027; η^2 = .028), with the healthy group reporting higher levels of interpersonal foreclosure (M= 18.64, SD= 5.77) than patients (M= 16.86, SD= 4.92). No additional significant differences were found for group membership. However, we found a significant main effect of gender for interpersonal achievement (F (1, 169) = 6.71, p=

.01; η^2 = .038), with females (*M*= 33.42, *SD*= 5.94) endorsing higher levels of interpersonal achievement than males (*M*= 31.07, *SD*= 5.85). Values for ideological and interpersonal identity can be found in Table II.

Identity as a Categorical Variable

The classification of patients and healthy adolescents into ideological and interpersonal identity status categories are presented in Table III and Table IV, respectively. For the ideological status, 19% of patients and 15.7% of controls scored below the cutoff points in three or four of the identity status categories and were thus classified as low profile. Furthermore, 17.9% of patients and 16.9% of controls were considered multi-dropped, given that they scored below the cutoff points in three or four of the identity status categories. The distribution of the two groups across the four ideological identity statuses was significantly different (χ^2 (5)= 14.72, *p*= .012). With respect to the interpersonal status, 11.9% of patients and 18% of controls were categorized as multi-dropped and 16.7% of patients and 15.7% of controls as low profile moratoriums. No significant difference was found in the distribution of the two groups across the interpersonal identity statuses (χ^2 (5)= 3.49, *p*= .624).

Quality of Life

We first examined whether group difference existed in the importance given to each of the nine areas of life measured in the QOLPAV. Results revealed significant differences in two areas, namely social belonging (*t* (172)= 2.63, *p*= .009) and community belonging (*t* (172)= 2.74, *p*= .007), with patients rating these areas as more important than did their healthy counterparts. Means and standard deviations can be found in Table V.

No significant difference was found in the distribution of the scores across the different categories of QOL (χ^2 (4)= 2.22, *p*= .70). As shown in Table VI, the vast majority reported positive QOL scores that ranged from adequate to very good. This was further supported by the lack of significant differences between the patient and control groups in their scores for the nine areas of life measured as well as in their overall QOL score. Similarly, no significant differences in perceived control over the QOL domains, and perceived opportunities for growth and development were found between the two groups. Means standard deviations and significance values for the overall scores can be found in Table VII.

Discussion

This study examined identity development and QOL in diabetic and renal transplant patients compared to healthy adolescents.

The first goal of this study was to assess the identity development of teenagers with a renal transplant or a diagnosis of Type 1 diabetes and conduct comparisons between this sample and a sample of healthy teenagers. Our results revealed that a similar proportion of adolescents with a chronic illness and their healthy counterparts attained the ideological achieved identity status. However, a greater number of healthy teenagers sought experiences or adopted parental commitments in the areas of religion, politics, occupation and lifestyle, rendering their ideological identity status as foreclosed or moratorium. In contrast, the patient group was mostly found in the diffused status suggesting a lack of both exploration and commitment in these areas. One may speculate that parents of adolescents with a chronic illness may be more focused on the immediate care and survival of their child rather than on the transmission of attitudes, values, and belief systems. As a result, these adolescents are less likely to be handed opportunities to explore and adopt specific ideological attitudes and values.

With respect to interpersonal identity, adolescents with a chronic illness reported similar levels of development as the control group. Surprisingly, the latter group reported significantly higher levels of interpersonal foreclosure, suggesting once again the adoption of strong commitments based on others' values and choices. It is noteworthy that our group of healthy adolescents consisted of students in a post-secondary institution. It is perhaps the case that, during such a time of transition between high-school and university, these adolescents were not yet ready to make their own decisions and relied more heavily on the values of others around them (e.g., friends).

Lastly, significant differences were found in levels of interpersonal achievement between males and females regardless of group affiliation, with the latter group reporting significantly higher scores than males. This result is consistent with previous studies (e.g., Phillips & Pittman, 2007) and may be due to girls maturing earlier than boys.

Overall, the results from the identity measure in our study illustrate that there are many similarities between patients and healthy controls. These results confirm Luyckx and colleagues' (2008) findings, which showed similar identity development between adolescents with diabetes and healthy adolescents. Similarly, Pacaud and colleagues (2007) conducted a cross-sectional study comparing the psychosocial maturation of diabetic patients and healthy controls ranging from 18 to 25 years in age. The researchers compared locus of control, social maturation, and responsibility and independence between the two groups. With regard to social maturation, they found the same percentage of young adults within each degree of social maturation (i.e., good, moderate, poor). Locus of control was also similar in the two groups. Overall, the authors concluded there were no differences in psychosocial maturation between healthy and diabetic young adults. Although their study did not look at identity development, it examined other important psychosocial concepts showing that few differences exist between healthy and chronically ill adolescents. Our study adds to the corpus of existing literature in the area of identity development in chronically ill adolescents, as it confirms previous findings in diabetic adolescents while also exploring the identity development of renal transplant adolescents.

It is important to note that studies that investigate identity development such as ours rely on subjective measures. Specifically, these measures explore the general concept of identity without looking at objective developmental milestones (e.g., for romantic relationships, having a girlfriend or boyfriend). The use of such measures may explain the lack of differences between healthy and chronically ill adolescents. To illustrate, in a study investigating the impact of a pediatric disease on the course of life of young adults who grew up with a chronic condition, Stam and colleagues (2006) reported that the patient group had achieved significantly fewer milestones than their healthy counterparts in autonomy, psychosexual, and social development domains. It is worth noting that Stam et al. (2006) used an objective measure of developmental milestones.

Our results show that both groups had low levels of identity achievement, with a high proportion of adolescents in the diffused or foreclosed identity statuses. Since they are about to enter adulthood, one may expect to find a higher proportion of late adolescents in the identity-achieved category. Kroger (2007) has given thought to this question following a review of longitudinal studies that examined identity status change during late adolescence and young adulthood. His review suggests that the percentage of identity-achieved individuals during this life period is relatively low and ranges from 13% to 49%. Similar results emerged in cross-sectional studies (Kroger, 2007). The participants recruited in our study were all at a critical period of their life: the time between late adolescence and young adulthood. Many were in their last year of high school or in their first year of post-secondary education, which represents a time of important changes. Based on Piaget (1977) and Whitbourne (1996), Kroger (2007) explains that in a time of identity disequilibrium, such as the new experiences of the end of high school and the start of post-secondary education, an individual may use identity assimilation, or identity status stability, to restore equilibrium. As such, “the lower incidence of transition to identity achievement beyond late adolescence may be that people are less likely to be open to potentially disequilibrating identity experiences (and the pain and distress they arouse), choosing life circumstances that confirm identity structures" (Kroger, 2007; p. 340). Seeing as both patient and control groups were found to be in the lower identity statuses given the life period during which they answered the questionnaire, it would be interesting to assess whether a lack of identity differences between the two groups would remain present at a later point in life.

The second goal of this study was to assess whether differences exist between adolescents with a chronic illness and healthy adolescents with regard to the importance they grant to the various areas in their life as well as their self-reported QOL in those same domains. Similar to identity development, no significant differences were found between patients and healthy controls with respect to QOL, with both groups expressing satisfactory levels. These results can also serve to explain that adolescents with a chronic illness develop in a context they perceive to be similar to the one of their healthy counterparts, rendering their identity development experience comparable. Meuleners and colleagues (2001) assessed the QOL of healthy and chronically ill adolescents using the QOLPAV. Their results revealed no significant differences between the two groups, with the majority of QOL scores distributed across the acceptable (48% for CI adolescents vs. 51% for the healthy group) and very good (36% for CI adolescents vs. 35% for the healthy group) categories. Studies focusing more specifically on diabetes or end-stage renal disease (ESRD) have also found comparable results. Wake, Hesketh, & Cameron (2000) revealed that, in their sample, diabetic adolescents reported their functional health to be similar to the healthy sample. The authors explained that diabetic adolescents may genuinely perceive their functional health to be similar to the one of healthy adolescents. A recent study of adolescents with ESRD and kidney transplant found that transplant patients reported higher levels of health satisfaction than patients on dialysis. Furthermore, transplant patients' scores matched the ones of a healthy population (Isolina, Malaga, Rajmil, Ariceta, Navarro et al., 2009).

It is interesting to note that our chronically ill group reported significantly higher levels of importance to social belonging and to community belonging. Similarly, several qualitative studies have reported that being normal was "the next most reported aspect of living with a chronic condition" after developing and maintaining friendships (Taylor, Gibson, & Franck, 2008, p. 3088). It is thus possible that these adolescents choose to ignore or minimize the impact of their illness in favor of feeling like their healthy peers. However, they behave in a way that reflects their understanding of the importance of developing supportive relationships.

Our study is not without limitations. Firstly, it is important to note that patients were recruited in pediatric hospitals on the days of their medical appointments. It is possible that those patients who did not attend their medical appointments or those who accepted to take part in the study but never returned their questionnaire experience more difficulties and lower QOL than those who did participate. Additionally, our study used questionnaires in order to investigate identity development and QOL. It is possible that the use of open-ended questions or semi-structured interviews would have highlighted more nuances in patients' answers. It is also noteworthy that the age, level of participants' education, as well as parents' education varied across the groups and may have impacted the level of identity development attained. Finally, given the small number of renal transplant patients, we combined the two groups of patients, which varied significantly across several variables. Furthermore, the combination of the two groups did not allow us to investigate whether differences exist between these two groups and the healthy controls.

Conclusion

Our results suggest that adolescents with a chronic illness perceive themselves as being very similar to healthy adolescents with respect to interpersonal identity development and QOL. At such a crucial time in their lives, it may be important for adolescent patients to put aside reminders of their illness and put emphasis on normalcy. Longitudinal studies should examine how chronic illness affects patients' identity and QOL over time. With respect to identity development, we investigated identity status at a time of great changes and transitions for these individuals. Future research should investigate identity development over a longer period and include young adulthood. As well, the assessment of identity development via questionnaire is subjective and reflects the adolescents' perception of their own identity. Additional studies should explore identity development in conjunction to the achievement of specific milestones in healthy and chronically ill young adults over time. Similarly, more in depth and nuanced research (e.g., using a qualitative methodology) should examine whether chronically ill and healthy adolescents express themselves similarly with regards to their QOL.

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Table I

Demographic Characteristics

Characteristic	Patients N	Patients Percentage	Controls N	Controls Percentage
Gender Number of females	48	56%	52	58%
Cultural background				
Caucasian	66	78%	59	66%
African American	2	2%	5	6%
Other	13	15%	21	23%
Current status				
Full time student	27	32%	50	56%
Full-time student working part-time	34	40%	37	41%
Other	23	27%	3	3%
Level of education				
Post-Secondary	52	62%	90	100%
University	3	4%	-	-
11th grade	18	21%	-	-
10th grade or less	11	13%	-	-
Living with parents				
Yes	75	88%	81	90%
No	10	11%	8	8%
Parents' marital status				
Married	54	64%	65	72%
Divorced	12	14%	9	10%
Separated	9	11%	8	9%
Other	9	11%	8	9%
Siblings				
Yes	74	88%	81	91%
No	10	12%	8	9%
Mother's level of education				
High school	23	27%	22	25%
Some college	27	32%	14	16%
Graduate studies	26	31%	40	45%
Father's level of education				
High school	32	39%	16	18%
Some college	13	16%	19	21%
Graduate studies	26	31%	41	46%

Table II

EOMEIS-II Identity Values for Patients and Healthy Controls

	Patients		Control		Significance
	Male	Female	Male	Female	
Ideological diffused	30.00 (5.71)	27.09 (7.32)	25.82 (6.83)	26.33 (5.56)	*p* =.035*[1]
Ideological foreclosed	19.19 (6.39)	18.32 (5.45)	21.38 (6.33)	21.00 (7.92)	*p*= .023*[2]
Ideological moratorium	24.86 (7.23)	24.79 (5.86)	25.03 (6.62)	25.40 (5.55)	NS
Ideological achieved	30.57 (6.17)	32.62 (7.49)	32.08 (4.69)	32.94 (5.28)	NS
Interpersonal diffused	24.00 (6.40)	21.32 (5.78)	23.58 (5.71)	23.33 (4.81)	NS
Interpersonal foreclosed	16.57 (5.29)	17.08 (4.67)	20.05 (5.66)	17.63 (5.68)	*p*= .027*[3]
Interpersonal moratorium	24.89 (6.33)	25.06 (6.26)	25.14 (4.92)	25.88 (6.44)	NS
Interpersonal achieved	31.46 (6.57)	33.26 (6.48)	30.68 (5.08)	33.58 (5.46)	*p*=.010*[4]

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[1] A main effect of group was found with patients endorsing higher levels of ideological diffusion in comparison to the healthy group.

[2] A main effect of group was found, with healthy adolescents endorsing higher levels of ideological foreclosure in comparison to the patient group.

[3] A main effect of group was found with healthy adolescents reporting higher levels of interpersonal foreclosure in comparison to the patient group.

[4] A main effect of gender was found with respect to interpersonal achievement with girls reporting higher levels of interpersonal achievement in comparison to boys.

Table III

Distribution of the Sample in Each Ideological Status

Ideological Status	Group	
	Patient	Controls
Diffusion	27 32.1%	13 14.6%
Foreclosure	9 10.7%	25 28.1%
Moratorium	5 6.0%	11 12.4%
Achieved	12 14.3%	11 12.4%
Multi-Dropped	16 19.0%	14 15.7%
Low Profile Moratorium	15 17.9%	15 16.9%

Table IV

Distribution of the Sample in Each Interpersonal Status

	Group	
	Patient	Controls
Diffusion	18 21.4%	19 21.3%
Foreclosure	16 19.0%	21 23.6%
Moratorium	11 13.1%	10 11.2%
Achieved	15 17.9%	9 10.1%
Multi-Dropped	10 11.9%	16 18.0%
Low Profile Moratorium	14 16.7%	14 15.7%

Table V

Values for Importance and Satisfaction

Domain	Group	N	Mean	SD	Significance
Importance Physical Being	Patient	85	3.90	0.55	*p*= 0.99
	Control	89	3.90	0.63	
Importance Psychological Being	Patient	85	4.05	0.60	*p*= 0.37
	Control	89	3.96	0.72	
Importance Spiritual Being	Patient	85	3.66	0.67	*p*= 0.84
	Control	89	3.68	0.78	
Importance Physical Belonging	Patient	85	3.83	0.69	*p*= 0.61
	Control	89	3.77	0.71	
Importance Social Belonging	Patient	85	4.04	0.63	*p*= 0.01*[i]
	Control	89	3.81	0.55	
Importance Community Belonging	Patient	85	3.98	0.54	*p*= 0.007*[ii]
	Control	89	3.74	0.63	
Importance Practical Becoming	Patient	85	3.49	0.64	*p*= 0.40
	Control	89	3.41	0.64	
Importance Leisure Becoming	Patient	85	3.69	0.64	*p*= 0.51
	Control	89	3.62	0.71	
Importance Growth Becoming	Patient	85	4.26	0.57	*p*= 0.21
	Control	89	4.15	0.58	
Satisfaction Spiritual Being	Patient	80	3.52	0.72	*p*= 0.49
	Control	87	3.59	0.60	
Satisfaction Psychological Being	Patient	80	3.55	0.76	*p*= 0.47
	Control	87	3.47	0.79	
Satisfaction Spiritual Being	Patient	80	3.58	0.67	*p*= 0.90
	Control	86	3.59	0.70	
Satisfaction Physical Being	Patient	77	3.83	0.69	*p*= 0.10
	Control	86	3.65	0.68	
Satisfaction Social Belonging	Patient	77	3.78	0.74	*p*= 0.65
	Control	86	3.73	0.65	
Satisfaction Community Belonging	Patient	77	3.64	0.77	*p*= 0.69
	Control	86	3.59	0.68	
Satisfaction Practical Becoming	Patient	79	3.40	0.66	*p*= 0.53
	Control	87	3.33	0.62	
Satisfaction Leisure Becoming	Patient	79	3.62	0.74	*p*= 0.41
	Control	87	3.53	0.67	

Satisfaction Growth Becoming	Patient	79	3.63	0.79	*p*= 0.79
	Control	86	3.66	0.68	

[1] A significant difference was found with patients rating social belonging as more important than did healthy adolescents.

[2] A significant difference was found with patients giving higher ratings of importance to community belonging than did the healthy adolescents.

Table VI

Distribution of Quality of Life Scores

QOL Scores		Group	
		Patients N= 77	Controls N= 84
Very problematic	QOL < -1.5	1 1.3%	0 0%
Problematic	QOL between -.51 to -1.50	2 2.6%	1 1.2%
Adequate	QOL between -.50 to .50	22 28.6%	28 33.3%
Acceptable	QOL between .51 to 1.50	33 42.9%	38 45.2%
Very good	QOL > 1.51	19 24.7%	17 20.2%

Table VII

QOLPAV Values for Patients and Healthy Controls

QOLPAV Domain		N	Mean	SD	Significance
Physical Being	Patient	78	0.75	0.96	*p*= 0.12
	Control	87	0.97	0.85	
Psychological Being	Patient	78	0.83	1.09	*p*= 0.97
	Control	86	0.82	1.14	
Spiritual Being	Patient	78	0.90	0.93	*p*= 0.54
	Control	86	0.99	0.95	
Being	Patient	78	0.81	0.87	*P*= 0.38
	Control	86	0.93	0.86	
Physical Belonging	Patient	77	1.17	1.02	*p*= 0.13
	Control	86	0.93	0.95	
Social Belonging	Patient	77	1.20	1.11	*p*= 0.58
	Control	86	1.12	0.90	
Community Belonging	Patient	77	0.96	1.16	*p*= 0.84
	Control	86	0.93	0.97	
Belonging	Patient	77	1.10	0.95	*p*= 0.42
	Control	86	0.99	0.82	
ractical Becoming	Patient	78	0.67	0.83	*p*= 0.67
	Control	86	0.61	0.82	
Leisure Becoming	Patient	78	0.95	0.99	*p*= 0.38
	Control	86	0.82	0.90	
Growth Becoming	Patient	78	1.02	1.23	*p*= 0.98
	Control	85	1.03	1.03	
Becoming	Patient	78	0.88	0.90	*p*= 0.67
	Control	85	0.83	0.79	
Quality of Life Score	Patient	77	0.94	0.85	*p*= 0.92
	Control	84	0.93	0.75	
Control	Patient	79	3.86	0.68	*p*= 0.72
	Control	87	3.89	0.54	
Opportunities	Patient	78	3.47	0.72	*p*= 0.23
	Control	87	3.33	0.73	

Chapitre deux

Deuxième article

Patients’ perspective on factors that facilitate transition from child-centered to adult-centered health care: A theory-integrated metasummary of quantitative and qualitative studies

Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: A theory-integrated metasummary of quantitative and qualitative studies

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Abstract

The purpose of this review was twofold. First, to summarize systematically the state of the research conducted on the perspective of patients on transition from child-centered care (CCC) to adult-centered care (ACC). Second, based on this review of patients' perspective, to identify factors that facilitate transition to ACC. Using a metasummary methodology, we extracted, grouped, and abstracted the findings from 46 qualitative and descriptive quantitative studies involving patients before and/or after their transfer to ACC. Empirical results on transition fall into four groups: (1) patients' feelings and concerns; (2) patients'recommendations about transition; (3) outcomes after transfer; and (4) mode of transfer. Results are discussed within a theoretical transition framework that emphasizes the importance of fulfilling five conditions that will lead to successful transition. Given our findings, this synthesis and framework can be used to tailor transition care and direct future research.

Keywords: Adolescence/adolescent, adult-centered care, child-centered care, chronic illness, metasummary, systematic review, transition.

Résumé

La présente revue de littérature avait pour premier but de résumer de façon systématique les études sur la transition du milieu hospitalier pédiatrique au milieu hospitalier adulte basées sur la perspective des patients. Le deuxième but était de déterminer des facteurs pouvant faciliter l'expérience de transition au milieu hospitalier adulte en se basant sur les expériences de ces patients. À l'aide de la méthodologie du méta-résumé, nous avons procédé à l'extraction, au regroupement et à l'abstraction de résultats provenant de 46 études qualitatives ou de nature descriptive portant sur la transition de patients. Les résultats empiriques ont été divisés en quatre catégories, notamment (1) les sentiments et les préoccupations des patients, (2) les recommandations apportées par les patients, (3) les résultats suite au transfert en milieu adulte et (4) le mode de transfert utilisé. Les résultats de l'article sont discutés dans un cadre théorique de transition qui met l'emphase sur des conditions précises pouvant assurer une transition réussie. La synthèse des résultats et le cadre théorique proposé peuvent être utilisés pour adapter les soins en transition et guider de futures études.

Mots-clés : Adolescence/adolescent, soins hospitaliers adultes, soins pédiatriques, maladie chronique, méta-résumé, revue systématique, transition.

Introduction

Advances in medical technology have resulted in considerable improvements in the prognosis of chronic conditions and have increased the likelihood of chronically ill children attaining the stages of adolescence and adulthood (Blum et al., 1993; Scal, 2002). Chronic conditions are best defined as having a biological, psychological or cognitive basis, lasting at least 12 months, and necessitating compensatory assistance (e.g., medication) (Rew, 2005). The growing number of chronically ill adolescents who survive into adulthood has brought attention to the issue of transition of care, defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" (Blum et al., 1993).

The transition literature provides a comprehensive description of the differences that exist between child-centered care (CCC) and adult-centered care (ACC). These differences partially explain the challenges associated with transition and the reluctance with which it is often met by patients, parents, and health-care professionals. Furthermore, transition is a longitudinal and complex process as it occurs during the already challenging passage from adolescence to adulthood (Blum et al., 1993; Kelly, Kratz, Bielski & Rinehart 2002; Shidlow & Fiel, 1990) and it requires that the adolescent becomes increasingly mature and independent (Blum et al., 1993; Rosen, 2004). As they transfer to ACC, adolescent patients are required to adapt to a health care environment in which their physicians expect them to be fully autonomous, able to negotiate health care services, and make collaborative treatment decisions (Madge &

Bryon, 2002; Rosen, 1995). Additionally, because it is common for pediatricians in CCC to bestow both patients and their families with nurturing care (Madge & Bryon, 2002; Rosen, 1995), patients often perceive the process of transition as a life event that involves the loss of respected and loved ones (Landau, 1995; Madge & Bryon, 2002; McDonagh, 2005; Shaw, Southwood & McDonagh, 2004).

Additional challenging aspects of transition may stem from differences in the culture of care in each environment. Pediatricians have been described as often developing a longstanding emotional relationship with their patients and sometimes having difficulty trusting their patients' level of independence, which can reduce the chances of a successful transition (Viner, 1999). In contrast, practitioners in ACC who have not known their patients through childhood and adolescence, may be less attuned to the context in which patients continue to live in during their young adulthood (e.g., their family) and to the multifaceted needs of adolescents and young adults (Stehl, 2005).

The realization of the differences that exist between CCC and ACC, in conjunction with the awareness for the growing need for transition care has inspired the elaboration of a number of clinical recommendations and consensus statements (e.g., AAP, AAFP, ACP 2002; Blum, 2002; Rosen, Blum, Britto, Sawyer & Siegel, 2003; Viner, 1999) intended at increasing the likelihood that transition will occur smoothly and result in continuity of care for the patient (e.g. Cameron, 2001; Dabadie et al., 2008). This awareness has also inspired a body of research on several aspects of transition of care. While each study has the potential to advance our knowledge on specific aspects of the transition process, it is important to periodically summarize and integrate the body of knowledge generated in one area (Petticrew & Roberts, 2006). It can also be useful to focus on the unique perspective of certain actors (e.g., patients), as their subjective experience is likely to impact greatly on the outcome of any process including transition.

To our knowledge, no systematic review has been conducted to summarize transition research that focuses specifically on the perspective of patients and on their experience of what leads to a smooth transition. We set out to summarize the empirical literature with two objectives in mind: 1) to describe the state of the empirical transition literature completed thus far pertaining to chronically ill adolescent and young adult patients; and 2) to identify factors that potentially lead to a smoother transition to ACC.

Methods

Retrieval

We retrieved articles by searching three electronic databases (MEDLINE, PsycINFO, CINAHL) using variations and Boolean connections of terms related to transition (e.g. transfer and adolesc* and care; transition and adolesc* and care). We increased the database searches by scrutinizing the retrieved articles' references to identify additional relevant publications. The search was last updated in April 2009.

Inclusion and exclusion criteria. To be included in our review, articles had to: a) focus on adolescents and/or young adults with a physical chronic illness; b) examine empirically patients' transition experience, before or after the transfer took place using a quantitative or qualitative methodology; c) be published in an English or French peer-reviewed journal. The review spanned the last 15 years based on the sizeable increase in transition research that has occurred during this period. Excluded from our review were clinical recommendations, theses, studies conducted among health-care professionals, and transition studies involving patients with mental illness (e.g., ADHD, autism), learning disabilities or cognitive impairments. Forty-six articles met these criteria and were included in our review.

Extraction, abstraction, and synthesis of the research findings. To synthesize the findings from the retrieved articles, we chose the metasummary method, which encourages the integration of both descriptive quantitative and qualitative studies. The research imperative behind the metasummary is to be inclusive, and its philosophy is to recognize that findings from both qualitative and descriptive quantitative studies are often similar in form (e.g., highlight similar issues) and in mode of production (e.g., convergence in sampling) (Sandelowski, Barroso, & Voils, 2007). The metasummary thus allows researchers and clinicians to make the most of the available empirical literature and to create an up-to-date synthesis in an area of interest (Sandelowski et al., 2007).

The metasummary approach seemed particularly fitting for our stated purposes for two reasons. Firstly, in light of the relatively small number of empirical studies in the area of transition of care, we deemed that using a method that would allow the integration of qualitative and quantitative studies would permit us to produce an optimal synthesis. Secondly, studies conducted in the field of transition often show similarities in findings and in the way the research was conducted. As such, the results are likely to be highly comparable and amenable to being combined in one cohesive whole.

A metasummary is conducted in three steps. First, findings are extracted from each study, which means lifting the actual findings and separating them from references to findings from other studies, descriptions of analytical procedures, or discussion of the meaning and significance (Sandelowski et al., 2007). This was done by the first author (TL). Second, once extracted, findings that are judged to be topically similar are grouped together. This was done by two of the authors (TL, MS), who discussed grouping until a consensus was reached. The third step consists of abstracting and formatting the findings. In other words, once the findings are grouped, researchers work at creating a theme that preserves the complexity of their content while also eliminating redundancies. The abstracting and formatting was done by two of the authors (TL, MS). We took two additional steps to verify the accuracy of the final classification. One involved returning to each article in order to ensure that its findings were included. The other involved all authors reviewing and reaching a consensus that the final grouping and formatting most accurately reflected the body of findings reviewed.

Results

Studies' Findings

We reviewed studies that varied with regards to the methodology, the population and the timing of transfer (see Table I for specific characteristics). Following the extraction and abstraction of findings, we came to the conclusion that the body of findings reviewed falls into four broad categories: 1) patients' feelings and concerns; 2) patients' recommendations; 3) outcomes following transition; 4) effects of the mode of transfer.

1) Patients' feelings and concerns

Across several studies, patients described CCC as a familiar and comfortable environment, and reported attachment and feelings of trust toward their health-care providers (Brumfield & Lansbury, 2004; Hauser & Dorn, 1999; Kirk & Clayton, 2006; McCurdy et al., 2006; Miles, Edwards, & Clapson, 2004; Moons, Pixten, & Dedroog, 2009; Patterson & Lanier, 1999; Reiss, Gibson, & Walker, 2005; Sawyer et al., 1998; Soanes & Timmons, 2004; Tuchman, Slap, & Britto, 2008; Zach et al., 2003). Recent findings suggest that the main barrier patients faced following transition was to "detach themselves" from the pediatric team (Malbrunot-Wagner et al., 2009). Owing to their attachment to CCC, patients have reported feeling reluctant to leave behind health-care providers who had been taking care of their needs for years (Boyle, Farukhi, & Nosky, 2001; Hauser & Dorn, 1999; Miles et al., 2004; Sawyer et al., 1998) and being scared to move to ACC (Boyle et al., 2001; Wiener, Zobel, Battles, & Ryder, 2004). Being followed by the same pediatric providers for lengthy periods of time has been associated with reports of difficulty and concerns regarding transition to ACC (Boyle et al., 2001; Shaw et al., 2004). However, patients who did not feel attached to CCC expressed readiness to transfer in contrast to patients who felt attached and delayed the transfer (Miles et al., 2004).

Furthermore, having had prior negative experiences in ACC or having heard about other patients' negative experiences in ACC (Hauser & Dorn, 1999, Reiss et al., 2005; Tuchman et al., 2008) increased patients' concerns that the quality of care in ACC would not be comparable to the one received in CCC (Boyle et al., 2001). Patients have also voiced the fear that ACC providers would lack knowledge about early onset illnesses (Hauser & Dorn, 1999; Kirk & Clayton, 2006; Reiss et al., 2005; Tuchman et al., 2008; Westwood, Henley, & Wilcox, 1999; Wiener et al., 2004). However, patients felt reassured when their CCC providers showed trust in the ACC providers to which they were referred (Brumfield & Lansbury, 2004). Additional concerns included not knowing what to expect in ACC, not liking the ACC environment, not trusting ACC providers, and patients having to retell their story and ensuring that medical records would be transferred to ACC appropriately (McPherson, Thaniel, & Minniti, 2009; Reiss et al., 2005; Sawyer et al., 1998; Soanes & Timmons, 2004; Steinbeck & Brodie, 2006; Tuchman et al., 2008; Visentin, Koch, & Kralik, 2006; Westwood et al., 1999). Importantly, not all patients report concerns regarding transition (Anderson, Flume, & Hardy, 2002; Dabadie et al., 2008; McCurdy et al., 2006; Visentin et al., 2006).

2) Patients' recommendations.

Providers' characteristics. Patients have described CCC as a patronizing environment but have also mentioned that ACC can be alienating (Shaw et al., 2004). Patients favor services that provide developmentally appropriate care and a balance between formality and "babying" (Dovey-Pearce, Hurrel, May, Walker, & Doherty, 2005; Miles et al., 2004; Shaw et al., 2004; Soanes & Timmons, 2004) and attach more importance to providers' interpersonal skills than to the environment of care (Shaw, Southwood, & McDonagh, 2006). Positive provider characteristics include being knowledgeable about illness, supportive, trustworthy, and flexible, as well as having the ability to treat the patient with informality, to express interest in aspects of the patient's life other than their medical condition, and to give patients choices and a sense of control (Dovey-Pearce et al., 2005; Miles et al., 2004; Moons et al., 2009; Patterson & Lanier, 1999; Reiss et al., 2005; Scott, Vallis, Charrette, Murray & Latta, 2005; Shaw et al., 2004; Shaw et al., 2006; Soanes & Timmons, 2004; Steinbeck & Brodie, 2006; Tuchman et al., 2008; Wray & Maynard, 2008; Zach et al., 2003).

Need for independence. Transition requires patients to show a certain level of independence and findings suggest that patients do wish for independence. Prior to transfer, patients have stated that they would like to be the ones responsible for their health care by gaining a sense of control over their health (Brumfield et al., 2004; Madge & Bryon, 2002; Ostlie, Dale, & Moller, 2007; Soanes & Timmons, 2004; Zach et al., 2003), by acquiring skills pertaining to their health care (e.g., scheduling appointments), and skills needed for future employment opportunities (Hauser & Dorn, 1999, Zach et al., 2003). Patients wanted to be able to talk to their doctor alone (Dovey-Pearce et al., 2005; Shaw et al., 2004; Zach et al., 2003; Shaw et al., 2006) and to be taken more seriously by their providers (Tuchman et al., 2008). Although they wanted independence, some patients have reported they still needed their parents' support and reassurance (Kirk & Clayton, 2006; Moons et al., 2009; Soanes & Timmons, 2004; Wray & Maynard, 2008).

Researchers have identified a number of barriers towards achieving higher levels of independence. Patients have reported being concerned that their parents would not let them be independent or let them visit the doctor alone (Hauser & Dorn, 1999; Ostlie et al., 2007; Patterson & Lanier, 1999), while other studies mentioned the lack of preparation for increased autonomy prior to transfer (Visentin et al., 2006), and patients feeling discouraged after failing to be assertive about their condition (Shaw et al., 2004). Importantly, it appears that many patients report wanting independence but do not necessarily understand what the newly acquired independence will entail. To illustrate, in one study patients stated they wanted to make decisions on their own but did not consider speaking to their doctor alone as important (Westwood et al., 1999). Patients' lack of desire for, or ambivalence towards, autonomous behavior may stem from an ambiguous preparation for self-care (Anderson et al., 2002), or from overprotective parents and health care providers who may give patients the indirect message that they are unable to take care of themselves (Anthony et al., 2009).

Preparation towards transition. The literature suggests that a number of patients are not adequately prepared for their transition to ACC (Kirk & Clayton, 2006; McPherson et al., 2009). Some patients have reported experiencing transition as an abrupt event (Kirk & Clayton, 2006; Malbrunot-Wagner et al., 2009; Pacaud, Yale, Stephure, Trussell, & Davies, 2005; Reiss et al., 2005; Russell, Reinhold, & Maltby, 1996; Shaw et al., 2004; Stabile et al., 2005; Wray & Maynard, 2008), feeling like they did not learn enough about the transfer event ahead of time (Anderson et al., 2002; Busse et al., 2007; Chatuverdi, Jones, Walker, & Sawyer, 2009; Ostlie et al., 2007;

Patterson & Lanier, 1999; Shaw et al., 2006), and lacking information about transition (Busse et al., 2007; Chatuverdi et al., 2009; Kirk & Clayton, 2006; Pacaud et al., 2005; Soanes & Timmons, 2004; Wray & Maynard, 2008). In contrast, patients appreciated the possibility of talking about transition with their providers and feeling involved in all the decisions pertaining to it (Kirk & Clayton, 2006; Madge & Bryon, 2002; Tuchman et al., 2008; Wray & Maynard, 2008).

A widely reported patient recommendation is the one of joint visits with providers from CCC and ACC, as well as visits to the ACC environment prior to the transfer (Anthony et al., 2009; Annunziato et al., 2007; Brumfield et al., 2004; Chatuverdi et al., 2009; Dabadie et al., 2008; Dovey-Pearce et al., 2005; Hauser & Dorn, 1999; Malbrunot-Wagner et al., 2009; McCurdy et al., 2006; McPherson et al., 2009; Miles et al., 2004; Patterson & Lanier, 1999; Scott et al., 2005; Stabile et al., 2005; Tuchman et al., 2008; Westwood et al., 1999;). Such visits reduced patients' fears and concerns about transition (Boyle et al., 2001; Chatuverdi et al., 2009; Dabadie et al., 2008; Kipps et al., 2002; Westwood et al., 1999) and provided them with an opportunity to create relationships with providers in ACC, to get to know a familiar face before transfer, and improved transition outcomes (Brumfield et al., 2004; Dabadie et al., 2008; Kipps et al., 2002; Miles et al., 2004; Visentin et al., 2006; Stabile et al., 2005). As well, patients have recommended longer initial visits in ACC (Scott et al., 2005; Steinbeck & Brodie, 2006), or meeting with ACC providers more frequently than usual right after transfer, as it can help create a relationship of confidence with new providers (Duguéperoux et al., 2008). Similarly, patients have also suggested having a mentor such as a patient who has already experienced transition (Chatuverdi et al., 2009; McCurdy et al., 2006; McPherson et al., 2009; Patterson & Lanier, 1999; Soanes & Timmons, 2004; Westwood et al., 1999).

Preparation for transition also includes teaching patients about their condition, their treatment, and other issues pertaining to adolescence, as well as encouraging them to engage in autonomous behaviors (Hauser et al., 1999; McCurdy et al., 2006; Ostlie et al., 2007; Patterson & Lanier, 1999; Reiss et al., 2005; Shaw et al., 2004; Soanes & Timmons, 2004; Wiener et al., 2004). It has been shown that transition programs can enhance patients' knowledge, readiness to transfer, and level of implication in self-care (McDonagh, Southwood, & Shaw, 2007; Wiener et al., 2004). Use of educational websites, newsletters, and drop-in groups has been associated with reduced drop out rates after transfer, lower rates of complications, and helping transferred patients "reconnect" with ACC (Van Walleghem, MacDonald, & Dean, 2008).

Additional recommendations put forth by patients include receiving information about ACC in various formats (i.e., written, verbal, internet, notice boards) (Brumfield et al., 2004; Hauser & Dorn, 1999; McPherson et al., 2009; Patterson & Lanier, 1999; Shaw et al., 2004; Stabile et al., 2005; Steinbeck & Brodie, 2006; Visentin et al., 2006; Westwood et al., 1999; Wray & Maynard, 2008). Patients wanted to know what they should expect in ACC with regards to the new clinic, their new providers, and the medical procedures (Chatuverdi et al., 2009; Miles et al., 2004; Moons et al., 2009; Steinbeck & Brodie, 2006). Similarly, patients would have liked to be made aware of the disparities in culture between CCC and ACC and the characteristics of patients seen in ACC (Chatuverdi et al., 2009; Hauser et al., 1999; Miles et al., 2004; Moons et al., 2009). In the same line of thought, patients have recommended having facilities for young adults or a transition clinic (Busse et al., 2007; Dovey-Pearce et al., 2005; Miles et al., 2004; Russell et al., 1996; Scott et al., 2005; Shaw et al., 2004; Steinbeck & Brodie, 2006; Westwood et al., 1999; Wray & Maynard, 2008).

3) Transition outcomes

Satisfaction following transition. Patients have voiced both positive and negative comments about the ACC environment. Positive comments include efficient ACC staff (Busse et al., 2007; Tuchman et al., 2008; Wray & Maynard, 2008), feeling like adults, having significantly more control over decision-making in comparison to CCC, and feeling more responsible about the management of their condition (Busse et al., 2007; Dabadie et al., 2008; Duguéperoux et al., 2008; Kirk & Clayton, 2006; Ostlie et al., 2007; Miles et al., 2004; Moons et al., 2009; Russell et al., 1996; Scott et al., 2005; Stabile et al., 2005; Tuchman et al., 2008; Wray & Maynard, 2008). Negative experiences include being confronted to older and sicker patients, resulting in patients feeling fearful about their own future (Busse et al., 2007; Chatuverdi et al., 2009; Malbrunot-Wagner et al., 2009; Miles et al., 2004; Ostlie et al., 2007; Wiener et al., 2004; Wray & Maynard, 2008). Negative comments also pertained to the loss of relationships developed in CCC (Dabadie et al., 2008; Kirk & Clayton, 2006; Malbrunot-Wagner et al., 2009; Miles et al., 2004; Moons et al., 2009; Scott et al., 2005; Shaw et al., 2004; Stabile et al., 2005; Tuchman et al., 2008; Wray & Maynard, 2008) and to the fact that provision of care in ACC was not carried out in a way that encompassed all of the patients' needs (Busse et al., 2007; Chatuverdi et al., 2009; Malbrunot-Wagner et al., 2009; Ostlie et al., 2007; Patterson & Lanier, 1999; Reiss et al., 2005). Patients have reported feeling that ACC providers' knowledge of their condition was not as developed as CCC providers' had been (Busse et al., 2007; Reiss et al., 2005; Shaw et al., 2004; Tuchman et al., 2008). Additional negative experiences in ACC included a lack of sensitivity and empathy (Busse et al., 2007; Chatuverdi et al., 2009; Dovey-Pearce et al., 2005; Ostlie et al., 2007; Pacaud et al., 2005; Shaw et al., 2004), feeling unable to ask questions (Dovey-Pearce et al., 2005; Pacaud et al., 2005), seeing a different doctor at every appointment (Busse et al., 2007; Dovey-Pearce et al., 2005; Ostlie et al., 2007; Stabile et al., 2005), long waits (Chatuverdi et al., 2009; Pacaud et al., 2005; Wray & Maynard, 2008), and not having enough time with the doctor (Busse et al., 2007; Wray & Maynard, 2008). In addition, patients have reported negative comments that are applicable to both CCC and ACC environments, namely a lack of coordination and communication between CCC and ACC (Busse et al., 2007; Ostlie et al., 2007; Pacaud et al., 2005; Shaw et al., 2004; Stabile et al., 2005), unexpected delays between the expected and actual transfer dates (Sawyer et al., 1998), and not receiving enough information prior to transfer (Busse et al., 2007; Kirk & Clayton, 2006; Moons et al., 2009; Ostlie et al., 2007; Pacaud et al., 2005; Shaw et al., 2004; Wray & Maynard, 2008).

Adherence following transition. A large number of studies have reported that attendance to medical follow-ups suffers a decline following transfer to ACC (Annunziato et al., 2007; Brumfield et al., 2004; Busse et al., 2007; Chatuverdi et al., 2009; Kipps et al., 2002; Koshy et al., 2009; Pacaud et al., 2005; Reid et al., 2004; Scott et al., 2005; Sparud-Lundin, Ohrn, Danielson, & Forsander, 2008; Stabile et al., 2005; Van Walleghem, MacDonald, & Dean, 2008). Additional studies have reported low self-reported scores on adherence following transfer (Wojciechowsky, Hurtig, & Dorn, 2002) and problems related to adherence to treatment such as unexpected graft loss (Annunziato et al., 2007; Chatuverdi et al., 2009; Watson 2002). Reasons that may explain problems in continuing follow-ups in ACC include time constraints (Scott et al., 2005) difficulty establishing rapport with new providers (Brumfield et al., 2004; Van Walleghem et al., 2008), patients' perceiving providers as not valuing them (Van Walleghem et al., 2008), feeling overwhelmed with the new environment of care (Van Walleghem et al., 2008), not receiving reminders of their appointments or lacking guidance (Pacaud et al., 2005; Scott et al., 2005; Stabile et al., 2005), and feeling "burnt out" on health care (Patterson & Lanier, 1999). It has also been hypothesized that decline in adherence is linked with the fact that adherence is dealt with more severely in CCC (Annunziato et al., 2007).

Certain patients' characteristics appear to be associated with satisfaction and good adherence following transfer. Patients' developmental maturity (Brumfield et al., 2004), older age, and consenting to the transfer (Duguépéroux et al., 2008; Miles et al., 2004;) have been associated with higher satisfaction with the ACC environment. Patients who were still dependent on their parents and were unable to take care of their own health lacked the skills required to adapt well to ACC (Brumfield et al., 2004) whereas better preparation and high self-efficacy (i.e., patients' belief they can take care of their health-related needs) before transition were related to a larger number of kept appointments in ACC (Wojciechowsky et al., 2002). Patients who showed poor adherence before their transfer also showed adherence problems in ACC (Busse et al., 2007; Kipps et al., 2002), whereas patients who had good control over their health in CCC did so as well in ACC (Orr, Fineberg, & Gray, 1996).

4) Mode of transfer

The mode of transfer used varies across centers, with some offering patients early and extensive preparation while others do not (e.g., Shaw et al., 2006). The ACC environment to which patients are transferred is also subject to variations (e.g., Kipps et al., 2002). A number of researchers have investigated the mode of transfer employed and its effects on patients' satisfaction and adherence to treatment. In an extensive investigation of the mode of transfer to ACC in four groups of patients, it was found that patients most satisfied with their transition were those who had been transferred to a young adult clinic within the same hospital and had met the providers before the transfer (Kipps et al., 2002). Higher dissatisfaction and a decline in clinic attendance were found in patients directly transferred to an adult clinic. Similarly, one longitudinal study that followed diabetic patients from one year before until one year after transition to ACC found that patients' health did not deteriorate following transfer. The authors hypothesized that their good results were due to the fact that their patients had taken part in a young adult clinic that focused on empowering patients to help them manage their diabetes independently (Orr et al., 1996). In the same vein, in a follow up study of patients admitted to a young adult clinic it was found that health-related outcomes improved significantly following several visits in the program (Holmes-Walker, Lleywllyn, & Farrell, 2006).

Discussion

The metasummary we presented provides a comprehensive synthesis of the available qualitative and quantitative descriptive literature on the experience of patients with physical chronic illness of their transition from CCC to ACC. Our approach allowed us to highlight the predominance of four themes that are central to this literature currently: patient's concerns and feelings regarding transition; patients' recommendations for transition; outcome of transition; and mode of transfer.

In an effort to discuss our findings in an organized way and to integrate them within a framework that can help guide future clinical practice and research, we sought a theory that would allow us to map the findings into an integrated, comprehensive whole. Using a theoretical framework helps to look at a phenomenon in a new way by highlighting important determinants and by encouraging reflection upon the potential interactions that may exist between the variables at hand (Kazdin, 2004). In research, a framework helps to think logically about an issue (Denzin, 1970; Shoemaker, Tankard, & Lasorsa, 2004) and it helps generate novel research ideas (Kazdin, 2004). In clinical practice, it helps assess which important determinants are present or attended to in a given program, and which ones are underrepresented or need increased attention.

One model that seems particularly well suited for our purposes is the transition model proposed by Schumacher and Meleis (1994). Their model was originally based on a review of the general literature on transition in an effort to highlight some of the universal properties of the transition process (Schumacher & Meleis, 1994). While transition to ACC comes with its own challenges, it does resemble other transition experiences and shares many features represented in the transition model. Furthermore, given that transition to ACC varies widely from center to center, using a theoretical framework allows one to view transition as a general process and address each element in a way that best fits patients' specific needs and resources available in a given environment of care.

The transitional framework identifies three indicators of a successful transition, namely subjective well-being, well-being in relationships, and role mastery (Schumacher & Meleis, 1994). Transfer to ACC would thus be considered successful if patients report satisfaction with their new environment of care and their new relationships with ACC providers, and are able to independently navigate the health-care system. The model further identifies specific conditions that are likely to influence the fulfillment of the three aforementioned indicators (Schumacher & Meleis, 1994).

The first condition involved in a successful transition to ACC refers to the *meaning* given to transition by patients and other individuals involved. Like any other transition that takes place during adolescence (e.g., the transition to puberty), the move from CCC to ACC should be imbued with positive meaning. We recommend that health-care providers and parents stress that the transfer is a normative event that reflects the achievement of an additional developmental task and that it is neither a form of abandonment nor punishment by the pediatric team.

The meaning of transition is closely related to the second condition involved in a successful transition, namely patients' *expectations* regarding their move to ACC. Knowing what to expect during a transition experience can alleviate the stress a patient is feeling (Schumacher & Meleis, 1994). While expectations can be influenced by previous experiences, "the frame of reference created through previous experience may or may not be applicable to a new transition" (Schumacher & Meleis, 1994, p. 122). Additionally, expectations about transition are likely to be shaped by pediatric providers' own attitudes and by contact with patients already transferred. In order to foster the construction of realistic expectations about ACC, we recommend that pediatric providers take the time to ask patients about their expectations of ACC (e.g., "What do you think it will be like? What do you think will be the same/ different?"). Asking open-ended questions will give providers an idea of their patient's expectations and, when needed, a chance to assist patients in adjusting these expectations. Informing patients about the differences that exist between the two environments can also help foster the development of realistic expectations.

The third condition for transition to be successful is patients' *level of knowledge and skills* prior to the transfer. The need for new knowledge at the time of transition has been well documented (Schumacher & Meleis, 1994) and is highlighted in our own findings. Based on our review and on patients' recommendations, we suggest that preparation begin early (preferably early in the teenage years) and include teaching patients to become increasingly autonomous. Although this recommendation is not novel, we add to it the importance of empowering patients while educating them. While informing patients about their condition represents an important step in promoting their autonomy, empowering someone means recognizing, promoting, and enhancing their abilities "to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their lives" (Gibson, 1991, p.339). Our review highlights the positive impact of empowerment on patients' levels of adherence to treatment.

The fourth condition for a successful transition involves *planning* (Schumacher & Meleis, 1994) and refers to more specific steps that need to be undertaken in order to make the process smoother. First, the timing of transfer needs to be discussed between patients and pediatric providers. In addition, it is preferable for pediatric providers to either refer patients themselves or provide patients with a list of potential ACC providers to contact. In numerous studies, patients have suggested that planning involve a joint visit including both CCC and ACC providers, meeting the ACC provider, or visiting the ACC environment, prior to transfer. Given that adolescent and young adult patients give precedence to trust in their relationships with health care providers, the opportunity of getting to know providers prior to transfer can be particularly beneficial and represents an excellent way of easing the patient's entry into a new environment.

The fifth condition refers to the *environment* and the resources it offers the individual in the midst of transition. Both CCC and ACC environments can offer patients several resources. In order to assist patients with unexpected events that may take place during the transition process (e.g., difficulty finding an ACC provider), it could be particularly useful to identify an individual (e.g., a transition coordinator) capable of answering patients' questions. Pairing a patient with a mentor who can be a guide and role model, is another option and perhaps sometimes more feasible (Schumacher & Meleis, 1994).

Setting up a transition clinic or young adult clinic represents opportunities to create an optimal environment for a successful transition. There exists several different models of such clinics (e.g., age or condition specific; housed in CCC, ACC or elsewhere) and their exact characteristics depend on the needs of a given patient population and perhaps even more so on the resources available to those who take leadership in their creation. Until empirical evidence shows what specific features most significantly impact outcome, we consider important that these clinics not be a mere extension of CCC but rather that their mission be on patient education and empowerment. Overall, a transition or young adult clinic should be an environment in which patients feel comfortable and where they can gradually learn to live with their condition in the adult world and become increasingly autonomous. Paradoxically, creating young adult clinics raises additional concerns regarding the next phase of transition to the "real" adult world. A summary of practical recommendations can be found in Table II.

Our review suggests that the transition literature is replete with transition studies that focus on patients' concerns and recommendations. While we were able to identify a few longitudinal studies, there remains a lack of such studies that may be best suited at describing the overall process and how several conditions can impact transition outcome. Furthermore, we believe that research will be best guided by the use of theoretical frameworks. In light of the transition framework presented, avenues that may be of particular interest include examining how the fulfillment of various conditions impact transition outcome and patients' perception of their adjustment and well-being post-transfer. Examples of research questions are included in Table II.

Our metasummary has limitations. First, we focused solely on physical chronic illnesses and our results cannot be generalized to other conditions for which transition to ACC represents an issue. Similarly, our review includes various chronic illnesses and it is difficult to ascertain that the results are generalizable to each condition equally. Furthermore, although we have made efforts to include all relevant research studies, it is possible that important studies were missed. Updating the present review in the future and using additional databases (e.g., EMBASE) is recommended.

Despite its limitations, the present synthesis is unique in how it presents patients' perspective and the use of a transition framework to discuss the results will allow clinicians to reflect upon how to assess and improve their current practice, and will provide researchers with one possible theory to guide future investigations.

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Table I

Matrix of the reviewed studies, their methods, and general findings.

Lead author	Year	Sample size	Sample Characteristics	Condition	Sample design	Study design	Findings
Anderson	2002	313	Age: 20- 43 M = 34.5	Cystic fibrosis	Non random	Quantitative Survey Post transition	Patients' feelings, suggestions, and transition experiences.
Anthony	2009	14	Age: 12-18 M =15.7	Cardiomyopathy and congenital heart disease	Convenience	Qualitative phenomenological Pre transition	Patients' feelings, perceived differences between CCC and ACC, recommendations for transition program.
Annunziato	2007	14	Ages 21-35 M =30.64	Liver transplant	Non random	Quantitative Medical file review Post transition	Lower adherence post transition in comparison to two control groups.
Boyle	2001	52	Ages: 18-39 M = 28.8	Cystic Fibrosis	Non random	Quantitative Pre: questionnaire Post: interview	Patients' concerns pre transfer. Higher concerns in patients who had not met ACC providers and who had been in the same CCC for longer.
Brumfield	2004	6	Ages 19-34 M = 24.16	Cystic Fibrosis	Opportunistic	Qualitative Retrospective interviews Post transition	Patients' attitudes and opinions about transition, important elements of a transition program and recommendations, psychosocial factors, impact of transition.
Busse	2007	101	Ages : NR M = 17.8	Type 1 diabetes	Non random	Quantitative Phone survey Pre and post	Decline in follow-ups post transfer. Patients' feelings about ACC environment and lack of

						transition	continuity with the same provider. Positive and negative aspects of transition. Patients' recommendations for transition
Chatuverdi	2009	11	Age: 18-23 M = 19.5	Renal transplant	Non-random	Quantitative Audits case notes Satisfaction questionnaire. Pre and post-transition	Lack of involvement in planning and not knowing who to contact in ACC. Nine patients remained stable following transfer. Lower attendance to clinic compared to CCC. Recommendations about transition.
Dabadie	2008	29	Age: 15.5-20.5 M: NR	Inflammatory bowel disease	Non random	Quantitative Retrospective Medical charts and questionnaire Post transition	Effective planning leads to successful transition. Importance of the joint visit between patients and providers from both CCC and ACC.
Dovey-Pearce	2005	19	Age: 16-25 M = 19.9	Type one diabetes	Convenience	Qualitative Semi-structured interviews and focus group Pre and post	Themes included diagnosis, continuity of staff contact, the influence of age upon care, interactions with staff, pros and cons of age-banded clinics, and suggestions for service development
Duguépéroux	2008	68	Age : 18-35 M = 21.6	Cystic fibrosis.	Non random	Quantitative Retrospective Pre and post transition	Patients were clinically stable, more independent, and more autonomous regarding their health care following the transfer. Before transfer, patients had been stable and had agreed to the transfer. Had joint visits.

Hauser	1999	22	Age 13-21 M = 16.2	Sickle cell disease	Convenience	Qualitative Focus groups Pre-transition	Patients' concerns, expectations, and preparation needs towards transition to ACC.
Holmes-Walker	2006	191	Ages 15-25 M = 18.9	Type 1 diabetes	Non random	Quantitative Longitudinal Pre and post transition	Program improved attendance to medical follow-ups and HbA1c levels. Patients continued to attend follow-ups several years following the start of the program.
Kipps	2002	229	M = 22.1	Type 1 diabetes	Non random	Quantitative Clinical records Interviews Levels of HbA1c Post transition	Patients directly transferred to adult clinics showed a greater decline in clinic attendance compared to those who attended a clinic for adolescents. High levels of HbA1c before transition were associated with a poor outcome post transition.
Kirk	2008	28	Ages: 8-19 M = NR	Complex health care needs	Purposive	Qualitative Interviews Pre and post transition	Patients reported concerns about transition due to the lack of preparation and lack of information. Patients elaborated on the differences between CCC and ACC and the positive and negative aspects of transition.
Koshy	2009	115	Ages: 18 -19.9 M = NR	Renal transplant	Non-random	Quantitative Descriptive; review of medical records Post transition	No increased risk of graft loss following transition. There are less hospitalizations: patients consult in emergency situations.
Madge	2002	21	Ages: 14-17	Cystic fibrosis	Non random	Quantitative	Patients' perception of ideal age

			M = 15			Survey Pre-transition	to transfer. Ratings of various aspects of transition planning. Majority of patients were unconcerned about transfer and looked forward to being independent.
Malbrunot-Wagner	2009	22	Ages 18-26 M = 22	Cystic fibrosis	Convenience	Quantitative Medical files and questionnaires Pre and post transition	Elaborate patients' characteristics. Problems encountered by patients during their transition experience.
McCurdy	2006	17	M = 21.3	Kidney, liver, and heart transplant	Convenience	Qualitative Interviews Post transition	Patients elaborated on the differences between the two environments and their feelings about leaving CCC. Patients made recommendations to ease the transition process.
McDonagh	2007	308	Ages: 11, 14, & 17 M =14.2	Juvenile idiopathic arthritis	Non-random	Quantitative, Repeated measures design Pre transition	Participation in program was related to better health related QOL at follow-ups compared to patients' baseline. Patients' knowledge and satisfaction also improved.
McPherson	2009	72	Ages 14 – 21 M: NR	Sickle cell disease	Non-random	Quantitative Postal survey Pre-transition	Knowledge about transition and readiness to transfer were low. Patients rated transition as important and wanted to learn more about it. Patients' concerns and suggestions to improve transition are also discussed.
Miles	2004	7	Ages 16-22	HIV	Convenience	Qualitative	Themes included patients'

			M =18.7		sampling	Interviews Pre and post-transition	preparation, feelings, and concerns towards transition. Transferred patients elaborated on the new environment, and the benefits and losses of transfer.
Moons	2009	14	Ages 15-17 M = 16.14	Congenital heart disease	Convenience	Qualitative Pre (n = 10) or post transition (n = 4) interviews	Transfer to ACC was viewed as normal by patients who felt too old to be in CCC. Patients found difficult to leave CCC. Patients need better information about transition and want the information to be given to them and not to their parents.
Orr	1996	82	Age* = 13.8-19.6 M* = 17.3 *Age at transfer	Type 1 diabetes	Non-random	Quantitative Prospective Pre and post transition	Glycemic control did not decline following transfer. Patients' glycemic control had been good before the transfer. Patients stayed in the same hospital but were followed by providers who encouraged self-management (empowerment).
Ostlie	2007	13	Ages 15-27 M = NR	Juvenile idiopathic arthritis	Convenience	Qualitative Focus groups Pre and post transition	Patients feel the need to be included in decision making and to receive more knowledge about their condition. Patients needed more information regarding and to be better prepared for their transfer.

Pacaud	2005	79	Age: 18-22 M = 20.5	Type 1 diabetes.	Non-random	Quantitative Survey Post transition	Patients reported a number of problems with their transition experience (loss of follow up, abrupt transfer, lack of information and resources). Patients want confidentiality, privacy, informality, information, short waiting periods, a telephone service.
Patterson	1999	7	Ages 17 – 33 M = 24.3	Various chronic illnesses	Convenience	Qualitative Focus groups Pre or post transition	Barriers to successful transition included the differences between CCC and ACC, late introduction to transition, parents who can't let go, being burnt-out on health care. Recommendations and strategies to improve transition.
Reid	2004	360	Age: 19-21 M = NR	Complex congenital heart defects	Non-random	Quantitative: questionnaire Qualitative: individual interviews Post transition	Predictors of a successful transition were: documented recommendations, patients' belief that they should receive care in ACC, older age at the last CCC visit, attending visits without parents, presence of comorbid conditions, and not using substances.

Reiss	2005	143	Ages: 13-35 M = NR	Various illnesses and special health care needs	Convenience	Qualitative Focus groups Pre and post transition	Patients perceived that CCC was better organized for their care. Patients reported they had been with the same CCC providers for a long period of time and had close and trustful relationships with CCC providers. Patients reported a number of negative interactions with ACC providers.
Russell	1996	7	Ages: 11-20 M: NR	Cystic fibrosis	Convenience sample	Qualitative Interviews Post transition	Themes: a) developmental tasks (i.e. patients were in the process of becoming more autonomous); b) transition: patients felt like adults once in ACC but mentioned the need for a adults in ACC but mentioned the need for young adult clinics.
Sawyer	1998	10	Ages: over 18 M = 22	Spina bifida	Convenience sample	Qualitative Interviews Pre and post transition	Patients were anxious about leaving CCC and developing new relationships with ACC providers. Dissatisfaction in 3 areas following transfer: delay between planned date of transfer and actual date, insufficient assessment by ACC, and uncertainty about their future care in ACC.
Scott	2005	75 questionnaires 19 interviews	Ages: 17-25 M = 20.15	Type 1 diabetes	Non random	Quantitative Questionnaires Qualitative Phone interviews Post transition	Lower attendance to CCC versus ACC clinic. Patients made positive comments about CCC. Recommendations for a smooth transition and description of ideal diabetes

							center.
Shaw	2004	12 adolescents 18 young adults	Ages: 13- 18 (adolescents) M: NR Ages: 19- 30 (young adults) M: NR	Juvenile idiopathic arthritis.	Random selection followed by convenience selection	Qualitative Focus groups Pre and post transition	Patients mentioned the need for a transition program that is: a) multidimensional; b) coordinated; c) supportive; d) developmentally and age-appropriate. Negative aspects of transition experience and recommendations are discussed.
Shaw	2006	308	Age: 10.9-18 M: NR	Juvenile idiopathic arthritis	Non random	Quantitative Cross-sectional and longitudinal Pre transition	Assessed patients' and parents' satisfaction before and after the implementation of a transition program. They report essential providers' characteristics. Improvements in patients' reported levels of satisfaction were found 12 months following program entry.
Soanes	2004	7	Ages 14-17 M: NR	Diabetes, renal failure, & cancer	Convenience	Qualitative Interviews Pre-transition	Identified5 main themes: a) need for comfort and familiarity; b) patients like informality; c) transition needs to be gradual; d) patients need care to be flexible; d) patients require support.
Sparud-Lundin	2008	104	Ages: 18-24 M (time of transfer) = 19.8	Type 1 diabetes	Non random	Quantitative. Review of medical files. Longitudinal Pre and post transition	Significantly more medical follow- ups in CCC in comparison to ACC. Follow ups in ACC suffer a significant decline over the years following transfer. Poor glycemic control was associated with more medical visits.

Stabile	2005	24	Ages: NR	Kidney, liver, double lung, heart, heart/lung, and small intestine transplant patients.	Convenience	Qualitative Semi-structured interviews Post transition	Patients elaborated on a number of challenges pertaining to the transfer to ACC such as leaving CCC, not receiving enough information, abrupt transfer, and a lack of communication between CCC and ACC providers. Positive aspects of transition include more freedom. Patients made suggestions to improve the transition process.
Steinbeck	2006	27	Ages: 16-25 M = NR	Various chronic illnesses (e.g. diabetes, CF, cancer)	Convenience	Qualitative Forum Pre and post transition	Patients elaborated on the differences they perceived between CCC and ACC and their feelings and concerns about transition. Patients made recommendations to improve the transition process.
Tuchman	2008	22	Ages 15-21 M = 18.2	Cystic fibrosis, sickle cell disease, inflammatory bowel disease, juvenile rheumatoid arthritis	Convenience	Qualitative Interviews Pre and post transition	Themes that emerged: patients' feelings about the timing of transfer, the role of parents' in the patients' transition, patients' attitudes and concerns before and during the transfer, patients attitudes following the transfer, and patients' suggestions.
Van Walleghm	2008	101 (older group) 82 (younger group)	Age (younger group) = 18 Age (older group) = 19-25	Type 1 diabetes	Non-random	Quantitative Cross-sectional Longitudinal Pre and post-transition	Forty percent of the patients in the older group dropped out of ACC following transfer in comparison to 11% of patients in the younger group who had access to the System Navigator Model prior to the transfer. The program also helped older

							patients reconnect with ACC.
Visentin	2006	10	Age: 15-18 M: NR	Type 1 diabetes	Convenience	Qualitative Interviews Pre transition	Patients expressed few concerns about transition but they were also unaware of the differences between CCC and ACC. None of the patients had received written information about transition but they would have liked to.
Watson	2000	20	Age*= 15.7 – 20.9 M* = 17.9 *At transfer	Renal transplant	Non-random	Quantitative; Review of medical records	Eight patients lost their graft following transfer to ACC. Graft loss was unexpected in 7 of those patients. Adverse psychosocial factors were present in the majority of patients who lost their graft or were transferred young.
Westwood	1999	21	Ages: 14-21 M: NR	Cystic fibrosis	Non random	Quantitative Cross-sectional Survey Pre and post transition	Patients mentioned the importance of independence. Patients expressed being worried and concerned about transfer to ACC. Concerns included not liking ACC, not knowing what to expect, and ACC providers' knowledge of CF. Patients recommended having a transition clinic.
Wiener	2004	12	Age: 9-25 M = 15.8	HIV	Non-random	Quantitative Questionnaire Longitudinal Pre-transition	Demonstrated that the identification of transition issues followed by an intervention improves patients' readiness to move on to ACC.
Wojciechowski	2002	18	Ages: 18-24 M = 20.3	Sickle cell disease	Non random	Quantitative Questionnaires	Out of 18 patients, 11 had received preparation. Patients

						Post-transition	who kept their first ACC appointments, had higher self-efficacy levels, had received better preparation, and had higher adherence scores.
Wray	2008	38	Ages: 17-20 M = NR	Complex cardiac disease	Non random	Postal survey Quantitative and qualitative (open-ended questions) Pre and post transition	Results included: a) aspects of CCC and ACC that are valued and aspects causing dissatisfaction; b) communication in ACC; c) care and interactions in ACC; d) patients' recommendations to improve transition.
Zach	2003	32	Ages 16-43 M = 28	Cystic fibrosis	Non-random	Quantitative and qualitative Questionnaire and interview Pre and post transition	Transition within a pediatric hospital. Importance of independence and being able to make their own decisions regarding health. Patients wanted services to be more adult oriented.

Table II

Clinical recommendations and examples of research questions on patients' transition to ACC based on a theoretical transition framework

Condition for successful transition	Clinical recommendations	Examples of research questions
Meaning given to transition by patients	Assess the meaning patients given to transition by asking open-ended questions (e.g. "Tell me what transferring to adult care mean to you"). Encourage patients to view the positive meaning of transition.	Do patients who perceive transition as a positive event show better (both subjective and objective) levels of readiness to transfer to ACC? Can help in reframing transition as a positive event improve outcome?
Expectations about transition and the ACC environment	Assess patients' expectations about the ACC environment using open-ended questions (e.g., "What do you think ACC will be like?; How do you think it will be similar/different than CCC?"; What will you be expected to do in ACC?") When needed, assist patients in adjusting their expectations.	To what extent do patients' expectations about ACC match their actual experience in ACC? To what extent do discrepancies between expectations and actual experience influence outcome?
Level of patients' knowledge and skills	Work with patients to increase condition-related knowledge and skills using empowerment. Encourage patients to understand the reasons they need medical follow-ups and treatment. In CCC encourage patients to attend medical visits alone. In both CCC and ACC encourage patients to ask questions and to be involved in making choices during medical follow-ups.	What is patients' level of knowledge and skills before their transfer to ACC? Is the relationship between knowledge and skills related to outcome? Is this relationship moderated by the patient-provider relationship?
Transition planning	Begin planning transition early. Have a clear discussion of transfer timing Refer patients to an ACC provider or provide them with a list of potential providers to contact.	For transition planning to be effective, when should it be initiated? What planning models or interventions are most effective in influencing transition outcomes?

	Provide patients with a copy of their medical file. Provide patients with clear written documentation on ACC. When feasible, organize a joint visit that includes CCC and ACC providers, the patient and parents or a visit to ACC.	
Environment	Resources should be made available in both CCC and ACC environments to help patients during the transition process. Identify a key individual who can answer patients' questions.	What resources are available to patients in each environment and which ones need to be made available?

Chapitre trois

Troisième article

Transition from child-centered to adult-centered care in patients with diabetes and renal transplant: Feelings towards transfer and evolution of self-determination and adherence across the transition process

Transition from child-centered to adult-centered care in patients with diabetes and renal transplant: Feelings towards transfer and evolution of self-determination and adherence across the transition process

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Abstract

Transition from child-centered care (CCC) to adult-centered care (ACC) can be a challenging process because of the differences that exist between the two environments. The self-determination theory (SDT) has established that patients who perceive their health care environment as autonomy supportive will feel motivated and competent in managing their condition and show increased adherence to their treatment. Guided by the SDT, we followed the transition experience of patients with Type 1 diabetes or a renal transplant 6 months before (n= 85), and 6 months (n= 49) and one year (n= 36) after their transfer to ACC. Results revealed patients generally felt ready to transfer. Following transfer, there was a decline in patients' perception of autonomy support and a significant increase in their sense of choice and their adaptation to ACC. Higher levels of autonomy support were also associated with feelings of satisfaction, motivation, competence and self-reported adherence. Results reveal the importance patients give to their healthcare environment.

Keywords: Transition, self-determination theory, autonomy support, adherence.

Résumé

La transition des soins du milieu pédiatrique au milieu hospitalier adulte peut s’avérer complexe comme processus étant donné les différences qui existent entre ces deux environnements. Selon la théorie de l’autodétermination, la perception de soutien de l’autonomie de la part du personnel médical est intimement liée à une plus grande motivation et un sentiment de compétence de la part des patients à l’égard de leur routine de soins ainsi qu’à une meilleure adhérence au traitement. Guidés par cette théorie, nous avons suivi l’expérience de transition de patients atteints d’un diabète de type 1 ou de patients ayant reçu une greffe rénale 6 mois avant leur transfert (n= 85) ainsi que 6 mois (n= 49) et un an (n= 36) après leur transfert au milieu adulte. Les résultats révèlent que les patients se sentent généralement prêts à transférer. Six mois suite au transfert, une baisse est retrouvée dans la perception du soutien de l’autonomie des patients. En revanche, un an suite au transfert, les patients rapportent une augmentation du sentiment de pouvoir choisir ainsi que la perception d’une plus grande adaptation au milieu adulte. Enfin, les résultats démontrent qu’un plus grand sentiment de soutien de l’autonomie est associé à des niveaux plus élevés de satisfaction, de motivation, de compétence, et de perception d’adhérence au traitement. Les résultats illustrent l’importance que les patients accordent à leur milieu de soins.

Mot-clés: Transition, théorie de l’autodétermination, soutien de l’autonomie, adhérence.

Introduction

Approximately 10 to 13% of adolescents are affected by a chronic condition that limits their daily functioning (Yeo & Sawyer, 2005). A chronic condition can be defined as any condition that has a biological, psychological or cognitive basis, that lasts for a minimum of 12 months, and that necessitates compensatory assistance such as medication (Rew, 2005). For adolescent patients with a renal transplant, adherence is pivotal as they have to adhere to a lifelong regimen of daily intake of immunosuppressors and regular medical follow ups, as well as follow a careful diet (Dobbels & al., 2005). Similarly, adolescents with Type 1 diabetes are another patient group for whom illness management is critical. The regimen includes daily blood glucose monitoring, administration of insulin and regulation of diet and physical activity, as well as regular calculation of appropriate care based on these activities (Iannotti, Nansel, Schneider, Haynie, Simons-Morton, Sobel et al., 2006).

While adherence is essential to the successful management of a condition, non-adherence to medication and to diet regimen is common in adolescents. A particularly challenging period for adherence occurs during the time that bridges the end of the teenage years and the entrance into young adulthood, a period that coincides with the transition from child-centered care (CCC) to adult-centered care (ACC). Researchers have observed a decline in young patients' attendance to medical follow-ups and in self-reported adherence to treatment following transfer from child-centered care (CCC) to adult-centered care (ACC) (see review, Lugasi et al., 2011). One may speculate about the role different healthcare practices play in patients' adherence behaviors. According to Geerts et al. (2008), transfer to ACC can be a risk at the medical and health-related quality of life levels given that the different characteristics of CCC and ACC can act as significant obstacles for a successful transition. For instance, while CCC healthcare providers have been described as overprotective, providers in ACC healthcare expect patients to be fully autonomous as well as equal collaborators in treatment decisions (Madge & Bryon, 2002; Rosen, 1995). Several studies have shown that adolescent patients prefer healthcare providers who appear trustworthy, informal, and flexible, and who foster in them a sense of control (Lugasi et al., 2011). This suggests that patients' attitudes towards their healthcare environment and towards providers may be a venue worth exploring to understand the changes that may take place in adherence to treatment in the process of transition from CCC to ACC. While researchers have made significant effort in describing the process of transition and its impact on adolescent and young adult patients, research using a theoretical framework to explore the issue is lacking.

The Self-Determination Theory

In recent years, the important role that psychological and social factors play in healthcare outcomes has become increasingly recognized (Williams, Frankel, Campbell, & Deci, 2000). A distinction has been made between health-care practitioners who are said to endorse a "patient-centered" attitude and those who primarily focus on the biological aspects of an individual's illness. In a "patient-centered" or "relationship-centered" patient-physician relationship, the health-care practitioner takes the patient's point of view into account, offers choices, and generally engages the patient in the various aspects of the treatment (Williams et al., 2000).

Due to the fact that many of the differences between CCC and ACC lie in the dissimilar patient and healthcare practitioner styles, the SDT offers a useful theoretical background in guiding research on transition from CCC to ACC. Williams and colleagues (2000) describe the SDT as a ‘model of human motivation that is relevant to understanding the link between relationship-centered care and patients’ motivation, behavior, family dynamics, health, and well-being’ (p. 81). The SDT distinguishes between two important concepts, namely autonomous versus controlled motivation. People experience autonomous motivation when their behaviors are accompanied by a sense of choice and volition. In contrast, controlled motivation is found in the instance that an individual feels pressured to behave in a certain way (Williams, McGregor, Zeldman, Freedman, & Deci, 2004). Furthermore, studies have found that people who feel autonomously motivated feel higher levels of competence in attaining goals such as managing their medical condition (e.g., Williams, Freedman, & Deci, 1998).

An additional important concept in the SDT is the one of autonomy support, which holds that autonomous motivation and higher feelings of competence will be present when one’s significant others are autonomy supportive (i.e., supportive of the individual’s feelings and choices) (Williams et al., 2004). Several studies have demonstrated a strong link between autonomy supportive physicians and good health outcomes. Williams et al. (1998) assessed patients’ long-term adherence to medication regimen and found autonomous motivation to be a strong predictor of adherence. Patients were also asked how they perceived their physician and results indicated that those who perceived their physician as autonomy supportive reported more reasons for complying with their medication regimen autonomously and showed better adherence than patients who perceived their physician as controlling (William et al., 1998).

More recently, Austin, Senécal, Guay, & Nouwen (2011) used the SDT to explore the ways in which contextual and motivational factors can explain personal adolescent characteristics' (i.e., age, gender, diabetes duration) impact on dietary self-care. It was hypothesized that greater autonomy support would predict higher autonomous motivation, greater self-efficacy with respect to dietary self-care, which in turn would improve. Their hypotheses were supported, with findings showing that autonomy supportive parents along with the perception that health-care practitioners provided teenagers with choice and information about dietary self-care were associated with higher levels of self-efficacy and feelings of autonomous motivation.

Research studies using SDT as a framework to gain a more thorough understanding of the impact of autonomy support on self-efficacy and adherence to treatment are numerous within the adult population. However, such studies are lacking within the adolescent population although they seem particularly relevant to understanding the transition process from CCC to ACC. As such, the aim of the present study was to use the SDT framework to understand transition from CCC to ACC.

Our objectives and hypotheses were as follows:

1) Firstly, we were interested in exploring the broader context of transition by assessing patients' feelings prior to their transfer as well as whether a relationship existed between their feelings and the level of satisfaction they reported in ACC.
2) Secondly, we set out to assess whether a change occurred in patients' QOL, perceived feelings of autonomy support, autonomous motivation, perceived competence and adherence across the transition process.
3) Thirdly, we hypothesized that patients' perception of health care providers as autonomy supportive would be associated with higher levels of autonomous motivation and perceived competence.
4) Lastly, we hypothesized that higher levels of autonomous motivation and perceived competence would be associated with higher levels of self-reported adherence to treatment.

Method

Procedure

Recruitment took place from two diabetes and three nephrology clinics at three university-affiliated hospitals in Canada. Patients were informed of the study by their doctor or nurse during their clinic visit. Those who expressed interest in receiving additional information pertaining to the study completed a consent form allowing the principal investigator (TL) to meet with them following their visit at the clinic or to contact them at a later time. Each patient was then met in person or contacted by phone and, if he or she indicated an interest in participating, was given a questionnaire. Dates of transfer, defined as the first appointment in ACC, were collected via phone. Patients were sent a second and third questionnaire six months and one year following their initial appointment in ACC. Following receipt of each questionnaire, the principal investigator mailed all patients a personal thank you card along with a ten-dollar compensation. Ethics approval was obtained from the ethics boards of all three hospitals. A professional translator with experience in the field of psychology translated the questionnaires.

Participants

Inclusion criteria were: being 17 years old or older, having a diagnosis of Type 1 diabetes or a renal transplant, having an approximate date of transfer to ACC; and having a sufficient command of French or English to compete questionnaires in either language. Of the 107 patients who agreed to participate, 85 (79%) returned the questionnaire. Common reasons patients gave for refusing to participate or for withdrawing from the study included lack of time, lack of interest, or feeling tired of participating in studies pertaining to their medical condition.

Measures.

Demographic questionnaire. Participants were asked questions pertaining to their current educational background, health history (i.e., presence of a medical condition, year of diagnosis, medication), current family and living situation. Prior to transfer, open-ended questions regarding patients' feelings about transition were also asked. Following transfer, questions were asked with respect to patients' overall transition experience. Lastly, patients were asked to rate their perceived satisfaction and adaptation to ACC on a scale of 1 to 10.

Transition Questionnaire. This questionnaire has been used previously to assess adolescents' feelings and concerns about transition to ACC (Stehl, 2005; Telfair et al., 1994). For the present study, patients responded to 13 items regarding their concerns towards transition and 13 items assessing their feelings towards transition. Patients were asked to rate each item on a 5-point Likert-type scale, where 0= not at all and 4= very much so. Lastly, patients were asked to rate on a 5-point Likert-type scale the likelihood they would adapt very well to ACC (0= not true to 4= very true).

The Self-Determination Scale (SDS). The SDS (Sheldon, 1995) is a questionnaire designed to assess an individual's tendency to function in a self-determined way. The questionnaire is comprised of ten items, with two 5-item subscales: awareness of self and perceived choice. The awareness of self subscale measures the individual's awareness of their feelings and their sense of self while the perceived choice subscale assesses whether they feel a sense of choice with respect to their behavior. Reliability coefficients for the awareness of self subscale were .67 and .68 for the French and the English versions respectively. For the perceived choice subscale reliability coefficients were .78 and .79 for the French and the English versions respectively.

Health Care Climate Questionnaire (HCCQ). The HCCQ (Williams, Grow, Freedman, Ryan, & Deci, 1996) is a 15-item questionnaire designed to assess patients' perceptions of the degree to which their caregivers are autonomy supportive versus controlling. Patients are asked to rate each item on a 7-point Likert scale where 1 stands for strongly disagree and 7 for strongly agree. Previous studies using the HCCQ have found reliability coefficients to range between .92 to .96. Cronbach alphas for our sample were .95 for the French version and .93 for the English version.

The Treatment Self-Regulation Questionnaire (TSRQ). The TSRQ (Ryan & Connell, 1989) is an instrument designed to measure autonomous (e.g., 'Exercising regularly and following my diet are choices I really want to make') and controlled motivation (e.g., 'I just do it because my doctor said to') towards following treatment for a medical condition. Respondents are presented with a stem (e.g., 'The reason I follow my diet and exercise regularly is…') that is followed by items that vary in terms of degree of autonomous motivation. Participants are asked to rate each of the 19 statements on a 7-point Likert-type scale ranging from 'strongly disagree' to 'strongly agree'. Reliability coefficients for both autonomous and controlled subscales have been found to be excellent and have ranged from .80 to .87 (Williams, Freedman, & Deci, 1998). In the present sample, reliability coefficients for autonomous regulation were .75 and .72 for the French and English versions respectively. For controlled regulation, Cronbach values were .76 for the French version and .87 for the English version.

Perceived Competence Scale. This 4-item questionnaire measures the degree to which patients feel they are able to manage various aspects of their care on a daily basis. Respondents are asked to rate their level of agreement with each item on a 7-point Likert-type scale (1= not true at all; 7= very true). Internal consistency was found to be approximately .80 (Williams & Deci, 1996; Williams, Freedman, & Deci, 1998). Similarly, the internal consistency coefficients in our sample were .78 for the French version and .79 for the English version.

Frazier Non-Compliance Inventory (FNI). The FNI (Frazier, Davis-Ali, & Dahl, 1994) is a self-report of adherence to medication and measures how often patients do not take their medication for general reasons (e.g., 'Because I am away from home'). It consists of 11 items respondents rate on a 5-point Likert-type scale. Internal consistency for the FNI has been reported to be 0.91 (Frazier et al., 1994). Internal consistency coefficients in our sample were .77 and .75 for the French and English versions, respectively.

Quality of Life Profile Adolescent Version (QOLPAV). The QOLPAV (Raphael, Rukholm, Brown, Hill-Bailey, & Donato, 1996) measures quality of life in adolescents. The questionnaire contains 54 items equally divided between three domains, namely *being*, *belonging*, and *becoming*, each further divided into three sub-domains. The *being* domain explores adolescents' perception of who they are by asking questions pertaining to their self-esteem, self-concept, and spirituality. The *belonging* domain explores adolescents' feelings of belonging to their environment in three areas, physical, social, and community. Physical belonging refers to adolescents' connection to their home, school, neighborhood and community, while social belonging refers to adolescents' connection to social environments such as family and close friends. Community belonging refers to the individual's access and involvement in social services, recreational programs, and community activities. The final domain, *becoming*, pertains to adolescents' achievement of goals and aspirations in the practical (e.g. work, school, volunteer activities), leisure (e.g. activities performed for pleasure and relaxation), and growth (i.e. improving skills and knowledge, adaptation to change) sub-domains.

For each item in the questionnaire, respondents are asked to rate individual importance and satisfaction on a five-point Likert scale (1 = not at all to 5 = extremely). Finally, 18 additional items relate to adolescents' perception of the amount of control and opportunities they have over the areas mentioned above. Although the control and opportunities scales are not included in the scoring of the QOLPAV, they can provide an additional context to interpret the QOL scores.

QOL is obtained by looking at the importance and satisfaction the adolescent gives to each item. Means are calculated for each of the three sub-domains for the being, belonging, and becoming categories. The three means are then averaged to obtain the global QOL score. Scores can range from a low of -3.33 where the individual expresses extreme importance but complete lack of satisfaction to a high of +3.33 where both high importance and high satisfaction are found. An overall QOL score of 1.50 or higher is considered very good and a score between .51 to 1.50 suggests an acceptable situation. Furthermore, scores ranging between -.50 to .50 indicate an adequate situation, while scores from -.51 to -1.50 are problematic. Scores less than -1.50 are considered very problematic.

Psychometric properties of the QOLPAV suggest that this questionnaire has good internal reliability, with a Cronbach alpha above .80, and good validity (Raphael et al., 1996). In our sample, internal reliability ranged from .60 to .94 for both French and English versions.

Statistical Analyses

Data was analyzed using the Statistical Package for the Social Sciences version 17.0 (SPSS). Demographic variables were analyzed using a combination of t-tests for continuous variables and chi-square analyses for categorical variables. Given the attrition rate across time, we entered our dependent variables (self-determination, adherence, and satisfaction and adaptation to ACC) in a series of paired sample t-tests with Bonferroni corrections. Paired sample t-tests were conducted on variables at Time 1 (T1) and Time 2 (T2), Time 1 and Time 3 (T3), and Time 2 and Time 3. Lastly, we conducted Pearson correlations to determine whether a relationship existed between feelings prior to transfer and adaptation and satisfaction following transfer as well as between self-determination variables and adherence to treatment.

Results

Participants' Characteristics

The final sample at time 1 (i.e., prior to transfer to ACC) consisted of 54 patients with Type 1 diabetes (males= 24; females= 30) and 31 patients with a renal transplant (males= 13; females= 18). No significant group difference was found in the distribution of gender across the two medical conditions (χ^2 (1, 85)= .05, *p*= .82). With respect to age, we found a significant difference, with patients with a renal transplant being older (*M* age= 19.48, *SD*= 1.02) than patients with diabetes (*M* age= 18.03, *SD*= .26) (*t* (83) = 9.96, *p* < .01). Similarly, a significant difference was found with respect to the age of diagnosis with diabetic patients being diagnosed at a later age (*M*= 9.62, *SD*= 4.16) in comparison to the age of renal failure diagnosis of the renal transplant group (*M*= 5.80; *SD*= 5.47) (*t* (83) = 3.64, *p* < .01). Additional demographic information is provided in Table I.

Attrition in the sample was observed at both follow-ups, with 49 (58% of the initial sample) and 36 (42% of the initial sample) patients remaining at time 2 and time 3 respectively. On average, the first follow-up took place approximately 6 months following transfer to ACC (*M*= 207.74 days, *SD*= 36.03 days) and the third at approximately one year following transfer to ACC (*M*= *398.83* days; *SD*= 59.79 days). Given the attrition rate, we first investigated whether differences could be found between patients who completed the study versus those who did not. To do so, we conducted t-tests on variables at Time 1. No significant differences were found with respect to all demographic variables assessed (age, age of diagnosis, gender, ethnicity, family status, level of education). However, significant differences were found with respect to the importance given to physical well-being, with patients who remained in the study rating physical well-being as more important (*M*= 4.04, *SD*= 0.56) than patients who dropped out of the study (*M*= 3.80, *SD*= 0.56) (*t* (83) = 2.04, *p* =.05). Those who remained also reported feeling more ready to transfer to ACC (*M*= 3.06, *SD*= 0.75) than those who left the study (*M*= 2.61, *SD*= 0.75) (*t* (77) = 2.66, *p* =.01). Similarly, patients who remained in the study perceived themselves as more competent in managing their illness (*M*= 5.89, *SD*= 1.01) in comparison to those who did not remain in the study (*M*= 5.01, *SD*= 1.33) (*t* (83)= 3.31, *p* = <.01). A trend was also found with respect to autonomous regulation (*t* (81) = 1.89, *p*= .06), with patients who remained in the study showing higher levels of autonomous regulation (*M*= 5.46, *SD*= 0.73) in comparison to those who abandoned the study (*M*= 5.06, *SD*= 1.20). Lastly, patients who remained in the study reported higher levels of adherence to their treatment prior to the transfer (*M*= 4.51, *SD*=0.36) in comparison to those who did not continue the study (*M*= 4.32, *SD*= 0.46) (*t* (83)= 2.15, *p*= .03).

Feelings and concerns about transition

The assessment of patients' feelings about transition revealed that 38% and 25% of patients reported being moderately ok and very much ok, respectively, with the idea of moving on to ACC. In the same vein, 58% of patients agreed it felt like it was the right time to transfer. Nonetheless, 42% of patients reported moderate to high feelings of uncertainty. Lastly, approximately 40% of patients reported some feelings of worry, nervousness, and anxiety to transfer to ACC (see Table II).

The primary concern reported by patients was to leave behind long known health care providers: approximately 29% of patients reported being moderately concerned and 24% reported being highly concerned. Furthermore, the second highly rated concern was the lack of information about what to expect in ACC, with 28% of patients reporting being moderately concerned and 7% being highly concerned. Thirdly, 20% of patients reported moderate concerns and 9% reported high concerns toward their ability to make decisions on their own. Taking responsibility for themselves was also among highly rated concerns, with 18% of patients reporting moderate concerns and 8% reporting high concerns (see Table III).

Overall, 16.5% highly agreed and 51.9% of patients agreed they felt they would adjust very well to ACC. However, 26.6% of patients reported they might adjust very well to ACC while 5.1% felt that adjusting very well to the new environment was unlikely (see Figure 1).

Differences in QOL, self-determination, adherence, satisfaction and adaptation across the transition process

Analyses revealed no significant differences in QOL across time except for a trend in physical well-being with an increase between Time 1 (*M*= .59, *SD*= 1.00) and time 3 (*M*= 1.01, *SD*= 0.87) (*t* (29)= 2.40, *p*= .06). With respect to patients' perception of their healthcare environment as autonomy supportive, we found a significant decrease between Time 1 (*M*= 5.72, *SD*= 1.01) and Time 2 (*M*= 5.23, *SD*= 1.12) (*t* (46)= 2.69, *p*= .03). Furthermore, we found a significant increase in patients' feelings of a sense of choice over their behavior between T1 (*M*= 3.53, *SD*= 0.88) and T3 (M= 4.02, SD= 0.74) (*t* (35) = 1.89, *p* = .01). No significant differences were found across time with respect to self-reported adherence to treatment. Lastly, although no significant difference was found in patients' satisfaction with ACC between T2 and T3, patients did report significantly higher levels of perceived adaptation to the new environment of care one year following transfer (*M*= 8.50, *SD*= 1.72) in comparison to 6 months following transfer (*M*= 7.29, *SD*= 1.76) (*t* (23)= 5.02, *p*= <.01). All values from paired sample t-tests can be found in Tables IV and V.

Readiness to transfer and perceived satisfaction and adaptation to ACC

We conducted Pearson correlations to examine whether a relationship existed between patients' perceived readiness to transfer at T1 and their perceived satisfaction and adaptation, as well as their adherence and perceived competence with respect to treatment following transfer. Our results suggest that patients who reported high levels of readiness to transfer also reported high levels of perceived competence at time 1 (*r*= .29, *p*= .01). However, readiness to transfer was not significantly correlated with perceived competence following transfer to ACC. Similarly, readiness to transfer was significantly correlated with adherence to treatment in CCC (*r*= .278, *p*= .01) but not following transfer to ACC.

Relationship between perceived autonomy support, autonomous motivation, and adherence to treatment

With respect to self-determination variables, we found that, prior to transfer, patients who perceived their health care providers as autonomy supportive also reported high levels of autonomous motivation (*r*= .29, *p*= .01) and high levels of perceived competence (*r*= .35, *p*= <.001) towards their treatment. Furthermore, perceived competence was significantly correlated with adherence to treatment (*r*= .38, *p*= < .001). Similarly, following transfer to ACC, our results show that the perception of health care providers as autonomy supportive was significantly correlated with perceived competence regarding one's own treatment (T2: *r*= .34, *p*= .02; T3: *r*= .40, *p*= .018). Patients who perceived their ACC health care providers as autonomy supportive also reported higher levels of satisfaction (T2: *r*= .36, *p*= < .01; T3: *r*= .68, *p*= <.01) and of perceived adaptation to the new environment (T2: *r*= .63, *p*= <.01, T3: r= .55, p= <.01). Lastly, we noted that the level of perceived competence reported prior to transfer was significantly associated with higher levels of perceived competence six months (*r*= .460, *p*= .02) and one year (*r*= .52, *p*= <.01) following transfer. Self-reported adherence to treatment prior to the transfer was also associated with adherence at both follow-ups (T2: *r*= .57*,* *p*= < .001; T3: *r*= .39, *p*= .03).

Discussion

The goal of our study was to follow the transition of patients with diabetes and patients with a renal transplant from CCC to ACC. Specifically, we explored their feelings and concerns prior to their transfer and assessed whether a relationship could be found with the feelings they reported following transfer. Moreover, we added to the body of literature on transition by using the SDT theory to explore whether changes exist across the transition process with respect to patients' self-reported feelings of autonomy support by healthcare providers, perceived competence, and adherence to treatment and the relationship between these variables. Patients' overall QOL was also assessed as a means of exploring the broader context during which transition took place.

With respect to patients' feelings and concerns prior to the transfer, our results suggest that most patients accepted the fact that the time had come for them to transfer to ACC. Despite feeling they would adapt well to ACC, patients did express concerns about leaving pediatric health care providers they had trusted for so long and having to face an unknown environment. Patients' responses to the open-ended questions offer additional evidence that leaving well-known health care providers and expressing uncertainty about what to expect in ACC were predominant concerns. Additionally, these results are in line with several studies in which patients' feelings about transition were investigated. Indeed, numerous studies have reported patients' description of CCC as a comfortable environment in which healthcare providers are well known and trusted (e.g., Hauser & Dorn, 1999; Miles et al., 2004; Tuchman, Slap, & Britto, 2008). Pediatric patients with conditions such as diabetes or renal failure generally receive medical care in the same institution from a young age. As such, it seems only natural for them to perceive leaving their health care providers and having to face an unknown environment as their predominant concerns.

Knowing what to expect represents an important component of a successful adaptation to a new environment, as it allows an individual to prepare on both emotional and practical levels. Research on transition has shown that patients are often unacquainted with what awaits them in ACC and frequently wished they had been made aware of the differences between the healthcare environments ahead of time (e.g., Hauser & Dorn, 1999; Moons et al., 2009). In the present study, results showed that patients who, in CCC, reported high levels of competence with respect to managing their medical condition also felt they would adapt very well to ACC. Although this relationship was found prior to the transfer, it did not translate into feeling competent in ACC, suggesting that patients' feelings of readiness towards the transfer may not predict how competent they feel in handling their condition in the new healthcare environment. It is possible that feelings of competence in CCC are more easily translated into the practicalities of managing their condition given that patients are followed more closely by their health care providers. However, feeling competent in CCC may not necessarily predict that patients will adapt well to the challenges of ACC given that they are often unsure of what will be expected of them in the latter environment.

Following transfer to ACC, our results show that patients reported higher levels of adaptation to the new milieu across time. Furthermore, patients reported feeling a higher level of choice over their behavior one year following the transfer. Once again, comments made by the patients following their transfer can help shed light on their feelings. We observed that a number of patients made comments indicating that they enjoyed the increased independence and the possibility of making their own decisions in ACC. While independence was appreciated, several patients reported they would have liked to receive more guidance in ACC. Furthermore, according to some patients, the transfer to ACC was more difficult since they had to see a different doctor at every appointment and by the lack of closeness they had with their new doctor. These findings are consistent with previous studies (e.g., Scott, Vallis, Charrette et al., 2005; Pacaud, Yale, Stephure et al., 2005) and highlight the idea that transfer to ACC could be made easier by a balance of independence and guidance.

The second goal of our study was to study transition using the SDT as a theoretical background. It is noteworthy that in our study as well as in numerous others, many of the concerns and recommendations raised about transition revolve around characteristics of the health care environment and its providers, illustrating the importance patients grant to such factors. Our results show that patients did perceive a difference in the level of autonomy support that was given to them in CCC and ACC, with a decline observed in the latter six months following the transfer. However, we did not find a significant difference between the levels of autonomy support reported before and one year following the transfer, suggesting that the first months following the transfer may be ones of significant adaptation for patients. Given that these initial months in ACC represent a time during which patients need to adjust to a new environment and create new ties, it may be more difficult for them to perceive the health care providers as autonomy supportive.

The hypotheses we made based on the SDT were partially supported. Prior to the transfer, we found that patients who rated healthcare providers as autonomy supportive also reported higher levels of autonomous motivation and perceived competence towards managing their condition. Furthermore, perceived competence was also associated with higher levels of adherence to treatment. These results are consistent with the SDT, which claims that healthcare providers who support patients by doing things such as listening to their point of view and providing them with options lead to higher levels of autonomous motivation and self-efficacy. Our hypotheses were partly supported following transfer. At the first follow-up, six months following the transfer, we did not find perceived autonomy support to be associated with autonomous motivation. However, autonomy support was associated with perceived competence in managing one's condition. Furthermore, perceived competence was associated with higher levels of self-reported adherence to treatment. Similarly, at the second follow-up one year following the transfer, perceived autonomy support from health care providers was linked to perceived competence. However, we did not find a relationship between perceived competence and self-reported adherence to treatment at that time. Our results illustrate the important impact autonomy support may have on patients' feelings of competence with respect to managing their medical condition. In the same vein, patients who perceived their healthcare providers as autonomy supportive also reported higher levels of satisfaction and perceived adaptation to ACC, once again lending support to the importance of a supportive environment.

Overall, our results did not show many significant changes across time. Self-reported QOL was found to be in an acceptable range and did not change across the transition process. Furthermore, patients did not report changes with respect to their feelings of perceived competence and their adherence to treatment. It is noteworthy that our participants reported an overall good QOL, which may have helped them navigate the challenges of the transition to ACC. In the same vein, it is important to view our results by carefully considering the attrition rate and by comparing the patients who remained in the study versus those who did not. We found important discrepancies between patients who only completed the first questionnaire and those who took part in both follow-ups. Prior to the transfer, the latter group awarded higher levels of importance to their physical well-being than the group who did not remain in the study. Similarly, patients who remained in the study reported higher levels of competence towards managing their medical condition, as well as higher levels of autonomy, feelings of readiness to transfer, and adherence to their treatment. These results lead us to believe that the patients who remained in the study across the follow-ups were initially better prepared to navigate the challenges of the ACC environment.

Our study is not without limitations. Firstly, the present results cannot be generalized to the general population of patients with diabetes and with renal transplant who undergo transition to ACC given the small sample size and the disparities that were found between patients who remained in the study and those who left prematurely. Unfortunately, we were unable to assess whether the patients who did not remain in the study following transfer experienced difficulties in ACC. Nonetheless, the areas in which the patients who remained in the study and those who did not differ provides important information to keep in mind for future studies. It would indeed be useful to assess whether patients with characteristics such as lower levels of perceived competence and lower levels of readiness to transfer are at an increased risk of experiencing difficulties and lower adherence to follow-ups and to treatment in ACC. An additional limitation of the study lies in the fact that adherence to treatment was measured by means of questionnaires. Future longitudinal studies using the SDT should assess adherence to treatment more systematically. Lastly, it is important to note that we conducted correlations to assess the association between variables, which does not inform us about causal relationships.

Conclusion

The present study adds to the body of literature on transition by using a longitudinal design in combination with the SDT theoretical framework. The feelings and comments reported by patients both before and after their transfer are in line with previous studies and reflect the importance patients grant to the relationship with their healthcare providers. Our results also show that feeling that one’s autonomy is adequately supported is associated with higher levels of autonomous motivation, perceived competence and adherence to treatment.

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Table I

Demographic Characteristics

Characteristic	Patients	
	N	Percentage
Gender		
Female	48	56%
Male	37	44%
Diagnosis		
Renal transplant	31	36%
Type 1 diabetes	54	64%
Cultural background		
Caucasian	66	78%
African American	2	2%
Other	13	15%
Current status		
Full time student	27	32%
Full-time student working part-time	34	40%
Other	23	27%
Level of éducation		
Post-Secondary	52	62%
University	3	4%
11th grade	18	21%
10th grade or less	11	13%
Living with parents		
Yes	75	88%
No	10	11%
Parents' marital status		
Married	54	64%
Divorced	12	14%
Separated	9	11%
Other	9	11%
Siblings		
Yes	74	88%
No	10	12%
Mother's level of éducation		
High school	23	27%
Some collège	27	32%
Graduate studies	26	31%
Father's level of education		
High school	32	39%
Some college	13	16%
Graduate studies	26	31%

Table II

Feelings reported by patients prior to transfer

	N	Mean	SD
Feeling ok with the idea.	84	2.79	.93
Feeling it is the right time to move on.	85	2.68	.99
Uncertainty	84	2.31	1.02
Feeling no control over the decision.	84	2.12	1.19
Nervousness	84	1.99	.93
Worry	85	1.93	.94
Excitement/happiness	84	1.90	.90
Fear	85	1.85	.84
Anxiety	85	1.82	.90
Neutrality/No feelings	84	1.81	1.02
Relief	85	1.58	.75
Feeling deserted/abandoned	85	1.15	.42
Anger	85	1.09	.37

Note: Feelings were rated on a scale of 1 to 4, where 1 referred to ‘Not at all’ and 4 to ‘Very much so’

Table III
Patients' concerns prior to transfer

	N	Mean	SD
Concerns about leaving CCC health care providers.	84	2.56	1.09
Concerns about lacking information	85	2.16	.90
Concerns about decision making	85	2.01	.98
Concerns about taking responsibility	85	1.95	.95
Concerns about getting to know new health care providers.	85	1.80	.97
Concerns about asking for information	85	1.75	.89
Concerns about new health care providers not knowing patient and understanding their condition.	85	1.72	1.02
Concerns about being treated as an adult.	85	1.68	.97
Concerns about getting to and from the clinic.	85	1.62	.89
Concerns about not being trusted by new health care providers.	85	1.48	.88
Concerns about getting health care providers to talk to patients instead of parents	85	1.44	.78
Concerns about whether or not parents would let patient answer or talk to health care providers.	85	1.35	.78
Concerns about being perceived as drug seeking when in pain or when needing medication.	85	1.33	.66

Note: Concerns were rated on a scale of 1 to 4, where 1 referred to 'Not at all' and 4 to 'Very much so'

Table IV

Differences in QOL across time

		N	Mean	SD	p value	Corrected p value
Physical being	Time 1	42	0.67	0.98	0.25	NS
	Time 2	42	0.84	1.14		
Psychological being	Time 1	42	0.77	0.97	0.36	NS
	Time 2	42	0.64	1.15		
Spiritual being	Time 1	42	0.75	0.80	0.52	NS
	Time 2	42	0.85	0.87		
Being	Time 1	42	0.73	0.78	0.72	NS
	Time 2	42	0.78	0.90		
Physical belonging	Time 1	42	1.05	0.98	0.55	NS
	Time 2	42	1.14	0.98		
Social belonging	Time 1	42	0.99	1.20	0.99	NS
	Time 2	42	0.99	1.07		
Community belonging	Time 1	42	0.76	1.06	0.86	NS
	Time 2	42	0.72	1.09		
Belonging	Time 1	42	0.93	0.94	0.89	NS
	Time 2	42	0.95	0.95		
Practical becoming	Time 1	41	0.60	0.91	0.92	NS
	Time 2	41	0.58	0.93		
Leisure becoming	Time 1	41	0.73	1.05	0.42	NS
	Time 2	41	0.87	1.24		
Growth becoming	Time 1	41	0.78	1.25	0.72	NS
	Time 2	41	0.70	1.22		
Becoming	Time 1	41	0.70	0.93	0.91	NS
	Time 2	41	0.72	0.99		
QOL	Time 1	41	0.78	0.84	0.80	NS
	Time 2	41	0.81	0.90		
			Time1 - Time 3			
Physical being	Time 1	30	0.59	1.00	0.02	0.06*
	Time 3	30	1.01	0.87		
Psychological being	Time 1	30	0.85	0.76	0.65	NS
	Time 3	30	0.93	0.89		
Spiritual being	Time 1	30	0.95	0.87	0.88	NS
	Time 3	30	0.97	0.91		
Being	Time 1	30	0.76	0.74	0.14	NS
	Time 3	30	0.97	0.75		
Physical belonging	Time 1	30	1.17	0.98	0.75	NS
	Time 3	30	1.21	0.96		

	Time 1	30	1.05	1.05	0.53	NS
Social belonging	Time 3	30	1.16	1.04		
Community belonging	Time 1	30	0.94	1.07	0.45	NS
	Time 3	30	1.06	0.92		
Belonging	Time 1	30	1.03	0.93	0.37	NS
	Time 3	30	1.14	0.91		
Practical becoming	Time 1	29	0.53	0.77	0.09	NS
	Time 3	29	0.74	0.85		
Leisure becoming	Time 1	29	0.77	0.94	0.29	NS
	Time 3	29	0.93	0.91		
Growth becoming	Time 1	29	0.99	1.09	0.30	NS
	Time 3	29	1.13	1.05		
Becoming	Time 1	29	0.76	0.82	0.09	NS
	Time 3	29	0.93	0.87		
QOL	Time 1	29	0.86	0.80	0.16	NS
	Time 3	29	1.01	0.80		

Time 2 - Time 3

Physical being	Time 2	23	0.64	1.18	0.12	NS
	Time 3	23	0.94	0.73		
Psychological being	Time 2	23	0.80	1.16	0.38	NS
	Time 3	23	0.94	0.94		
Spiritual being	Time 2	23	0.91	0.90	0.44	NS
	Time 3	23	0.78	0.81		
Being	Time 2	23	0.79	0.98	0.42	NS
	Time 3	23	0.89	0.70		
Physical belonging	Time 2	23	1.10	0.98	0.63	NS
	Time 3	23	1.16	0.79		
Social belonging	Time 2	23	0.91	1.21	0.47	NS
	Time 3	23	1.04	0.93		
Community belonging	Time 2	23	0.76	1.30	0.19	NS
	Time 3	23	1.03	0.98		
Belonging	Time 2	23	0.92	1.10	0.28	NS
	Time 3	23	1.08	0.82		
Practical becoming	Time 2	20	0.41	0.88	0.19	NS
	Time 3	20	0.63	0.86		
Leisure becoming	Time 2	20	0.71	1.29	0.37	NS
	Time 3	20	0.89	0.94		
Growth becoming	Time 2	20	0.65	1.18	0.13	NS
	Time 3	20	0.94	1.01		
Becoming	Time 2	20	0.59	1.02	0.12	NS
	Time 3	20	0.82	0.86		
QOL	Time 2	20	0.70	0.97	0.07	NS
	Time 3	20	0.92	0.76		

Table V

Differences in self-determination variables, adherence to treatment, satisfaction and adaptation to ACC across time

Variable	Time	N	Mean	SD	p value	Corrected p value
	Time 1- Time 2					
Awareness of self	Time 1	47	3.92	0.77	0.32	NS
	Time 2	47	4.03	0.81		
Perceived choice	Time 1	47	3.63	0.82	0.15	NS
	Time 2	47	3.83	0.81		
Autonomous regulation	Time 1	47	5.35	0.90	0.99	NS
	Time 2	47	5.35	1.02		
Controlled regulation	Time 1	47	3.86	1.15	0.90	NS
	Time 2	47	3.84	1.08		
Perceived autonomy support	Time 1	47	5.72	1.01	0.01*	0.03*
	Time 2	47	5.23	1.12		
Perceived competence	Time 1	47	5.52	1.23	0.50	NS
	Time 2	47	5.65	1.08		
Adherence to medication	Time 1	47	4.48	0.40	0.35	NS
	Time 2	47	4.42	0.58		
Adherence to other aspects of treatment	Time 1	47	4.48	0.55	0.84	NS
	Time 2	47	4.47	0.64		
	Time 1- Time 3					
Awareness of self	Time 1	36	3.92	0.76	0.15	NS
	Time 3	36	4.11	0.72		
Perceived choice	Time 1	36	3.53	0.88	0.003*	0.009*
	Time 3	36	4.02	0.74		
Autonomous regulation	Time 1	36	5.45	0.73	0.08	NS
	Time 3	36	5.64	0.65		
Controlled regulation	Time 1	36	3.71	0.91	0.14	NS
	Time 3	36	3.91	1.05		
Perceived autonomy support	Time 1	36	5.85	0.97	0.04	NS
	Time 3	36	5.40	1.25		
Perceived competence	Time 1	35	5.89	1.02	0.16	NS
	Time 3	35	5.62	1.20		
Adherence to medication	Time 1	36	4.51	0.36	0.86	NS
	Time 3	36	4.49	0.38		
Adherence to other aspects of treatment	Time 1	36	4.43	0.59	0.43	NS
	Time 3	36	4.36	0.65		

			Time 2- Time 3			
Awareness of self	Time 2	25	4.13	0.75	1.00	NS
	Time 3	25	4.13	0.68		
Perceived choice	Time 2	25	3.96	0.78	0.88	NS
	Time 3	25	3.98	0.76		
Autonomous regulation	Time 2	25	5.27	0.99	0.24	NS
	Time 3	25	5.50	0.63		
Controlled regulation	Time 2	25	3.81	0.94	0.69	NS
	Time 3	25	3.88	1.05		
Perceived autonomy support	Time 2	25	5.32	1.06	0.67	NS
	Time 3	25	5.39	1.36		
Perceived competence	Time 2	25	5.60	1.20	0.75	NS
	Time 3	25	5.68	1.20		
Adherence to medication	Time 2	25	4.43	0.61	0.37	NS
	Time 3	25	4.51	0.39		
Adherence to other aspects of treatment	Time 2	25	4.48	0.55	0.69	NS
	Time 3	25	4.44	0.61		
Satisfaction with ACC	Time 2	25	6.88	2.35	0.17	NS
	Time 3	25	7.78	2.20		
Perceived adaptation to ACC	Time 2	24	7.29	1.76	0.00*	0.00*
	Time 3	24	8.50	1.72		

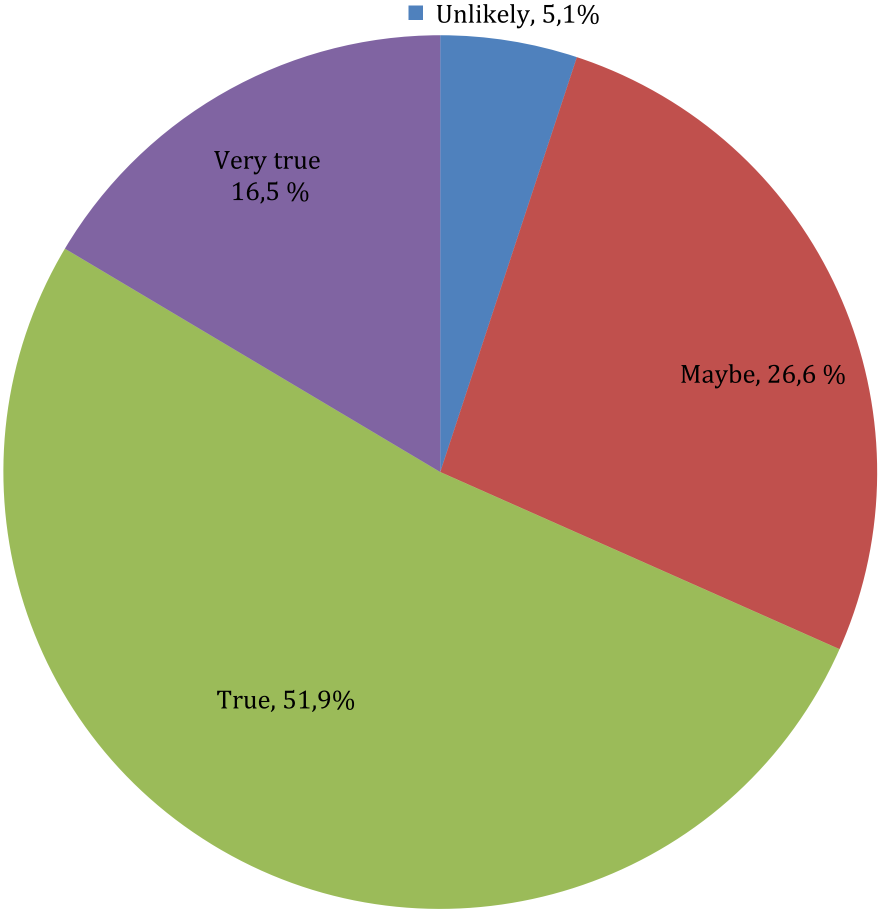

Figure 1. Percentage of patients reporting they feel they would adjust very well to ACC.

Discussion générale

General discussion

The increasing number of children with a chronic illness living well into adolescence and adulthood has created a challenge for the health care community, that of transition from CCC to ACC. While past studies on transition have identified factors that can have an impact on the transfer to ACC, few studies have used a longitudinal methodology or been are anchored in a theoretical framework. The aim of the present thesis was therefore to conduct a longitudinal, theoretically anchored project to investigate factors that facilitate transition both at the individual and contextual levels. The project was anchored in two theories, namely the theory of identity development (Erikson, 1963; Marcia, 1966) and the theory of self-determination (Deci & Ryan, 1985, 2000). It is positioned that these theories are useful in gaining an understanding of the factors that can have an impact on adolescent patients' transfer to ACC.

In the present section, a summary of the main results of each article and the contributions of the thesis will be highlighted. The limitations and clinical implications will also be discussed, along with recommendations for future research.

Summary of the main findings

The first goal of the thesis was to investigate the individual context in which transition of care took place. The theory of identity development was chosen because of the importance of this concept during adolescence. Specifically, the theory of identity suggests that the development of a healthy, achieved identity can help young adults navigate the challenges they may encounter throughout their adult life. Quality of life was investigated in order to provide the context in which identity development took place. Importantly, a control group was included in order to assess whether patients are comparable to their healthy peers with respect to identity development and QOL. Results of the first article suggest that, while differences were found with respect to ideological identity levels, adolescents with a chronic illness perceived themselves as being similar to their healthy counterparts with respect to their interpersonal identity and QOL. In keeping with other studies, adolescent patients seem to put an emphasis on normality instead of focusing on illness. Importantly, social and interpersonal relationships appeared to occupy an important place in the lives of these patients.

The second goal of the thesis was to assess facilitative factors of transition within the broader medical context in which transition of care took place. This goal was pursued in two separate articles. In the second article of the thesis, a metasummary of the literature on transition was conducted in order to identify factors that can facilitation transition based on patients' transition experiences. The review highlights four predominant themes (i.e., transition, patients' recommendations, the outcome of transition, and the mode of transfer used by the healthcare environment), leading to the identification of variables that can play a role in making the transition process smoother.

Results of the metasummary illustrate that patients' main preoccupation prior to their transfer to ACC was leaving the CCC healthcare providers to whom they feel strongly connected. Additional comments voiced by patients across studies reflected their concerns over the functioning of the ACC environment. The results of the metasummary also shed light on patients' recommendations on how they wish to be assisted throughout the transition process. The recommendations were divided into three areas, namely the characteristics patients strive for in their healthcare providers, their need for independence, and how they wish to be prepared for their transfer. Patients' recommendations with respect to their healthcare providers' characteristics go hand in hand with their wishes for independence. While patients across various studies have described CCC healthcare providers as 'babying' and the ones in ACC as 'alienating', they favor characteristics that respond to their need for gaining increased independence over their condition while simultaneously feeling support and reassurance from the adults in their environment. In the same vein, findings suggest that patients' wish to exert more control over their condition can be mitigated by their need for assistance from adults. Finally, recommendations made by patients included the need to be better prepared prior to their transfer to ACC, such as by receiving information about ACC ahead of time, visiting the adult clinic, having joint visits with healthcare providers from both environments, and by becoming well acquainted with their condition.

The outcome of patients' transfer to ACC was also highlighted in the metasummary and represents an additional aspect that can be informative as to ways of improving the transition process. Although patients have described positive aspects of ACC (e.g., being in an efficient environment, having more independence), negative comments have been noted, many of which are rooted in the patient-provider relationship. More specifically, patients' perception of the ACC providers as lacking sensitivity or as constantly changing from one appointment to the next has been associated with difficulty in establishing relationships based on trust as well as with poorer adherence to treatment in ACC. In addition, the shock of a new healthcare environment and the lack of guidance in comparison to CCC are also factors that have been associated with lower adherence to medical treatment.

Finally, studies investigating the method of transferring patients from one environment of care to another have given support to the recommendations made by patients. Transferring a patient from CCC to a young adult clinic has resulted in positive outcomes with respect to satisfaction and adherence to treatment. Similarly, clinics that focus on empowering patients prior to their transfer to ACC have also helped patients adapt better to the latter healthcare setting.

In the last article, patients' feelings, concerns, and satisfaction with respect to the transition process were investigated. Most importantly, the SDT was used in order to gain a comprehensive understanding of the transition process. With respect to patients' feelings about transition, it was found that most felt ready to transfer to ACC. As well, patients' who reported higher feelings of competence regarding the management of their condition also reported feeling more ready to transfer to ACC. Higher levels of adherence to treatment in CCC was also associated with higher levels of adherence in ACC. However, no significant relationship was found between readiness to transfer and adherence to treatment in ACC.

Although patients generally reported feeling ready to transfer, their two principal preoccupations reflected what had been highlighted in the metasummary and consisted of having to leave behind the pediatric team and having to face the unknown. Six months following their transfer, patients' perceived their healthcare providers in ACC as less autonomy supportive than those in CCC. However the same result was not replicated one year following transfer, with no significant differences in perceived autonomy support between CCC and ACC healthcare providers. With respect to self-reported adaptation to the ACC environment, patients' answers illustrated an improvement in adaptation between six months and one year following the transfer. No change was observed in patients' self-reported adherence to treatment throughout the transition process. Lastly, it was observed that patients who perceived their CCC providers as autonomy supportive also reported higher feelings of motivation and competence in the management of their condition. In ACC, these results were partially replicated, with higher feelings of autonomy support being related to higher feelings of competence in the management of one's condition. Importantly, the perception of autonomy support by the ACC healthcare providers was also associated with higher levels of satisfaction and perceived adaptation to the new environment.

Original contributions of the thesis

The present thesis brings forth several contributions to the body of literature on transition of care. In contrast to numerous past studies that have shed light on specific moments of the transition process (e.g., prior to or following the transfer), the components presented in the present thesis offer a more comprehensive understanding of the transition process. The use of well-established theoretical frameworks that focus on individual and medical contextual variables allowed for a more thorough understanding of the variables that can have an impact at different moments in the transition process.

The first theoretical framework chosen emphasizes the development of identity and the assessment of patients' QOL prior to their transfer to ACC, which helps to gain information on patients' individual context of transition. The literature on identity development in adolescents with a chronic illness has provided mixed results in this area. While some studies in the past showed poorer identity achievement in adolescents with a chronic illness, recent studies (e.g., Luyckx et al., 2008) have described identity development in this population as comparable to what is found among healthy peers. A similar pattern of comparable results between healthy adolescents and adolescents with a chronic condition has been observed with respect to QOL in the present study as well as in previous ones (e.g., Meuleners, Lee, & Binns, 2001).

While the results of the first article do not directly relate to transition of care, they remain of significance as they offer a better understanding of the individual context in which patients' transition takes place. Our results show that patients with diabetes and patients with a renal transplant perceive that they develop very similarly to their healthy counterparts. Furthermore, patients in our study gave significantly higher levels of importance to the areas of social and community belonging in comparison to the control group. These findings can be significant for healthcare providers in both CCC and ACC, as they are informative about the ways in which patients can be treated in each healthcare environment. Several studies have shown that patients tend to feel overprotected in CCC and patronized in ACC. The results of our study show that patients appreciate normalcy and, consistent with other studies, reveal patients' desire for a balance between being encouraged to be autonomous and receiving assistance from the adults in their environment. Comparably, a recent study by Huang et al. (2011) showed that the more parents were involved in their adolescents' care while in CCC, the less the adolescents showed interest and control over the management of their condition. These results indicate that healthcare providers in both CCC and ACC should foster a sense of independence in their patients.

The metasummary conducted as part of the second article of this thesis provides a systematic summary of the literature based on patients' transition experience. While reviews of the transition literature have been conducted in the past, this metasummary is the first, to our knowledge, to address the issue of transition by focusing on patients' perspective. The methodology that was chosen allowed for the determination of specific variables that impact transition before and after the transfer. Most importantly, an effort was made to synthesize the findings using a model of transition that allows us to view transition of care as a general process. Five conditions that can be fulfilled to ensure a smooth transition were identified and can likely be generalized to most healthcare environments and chronic conditions. Within each condition, specific recommendations were made at the clinical and scientific levels.

The third article of the thesis offers an overview of the transition process by using a theoretical framework, the SDT, which emphasizes variables that are most relevant to transition of care. More specifically, the results of this article illustrate the importance patients grant to the characteristics of both the CCC and the ACC healthcare environments. According to Hankins et al. (2012), “one of the most critical initial steps in ensuring adequate continuity of care during the transition from a pediatric to an adult-oriented medical setting is to identify and establish a relationship with the new health care provider” (p. 46). Prior to transferring to ACC, patients across numerous studies have mentioned finding it difficult to leave a comfortable environment in which they felt cared for by familiar healthcare providers. Our study replicated these findings, showing that the transfer to ACC is accompanied by a feeling of leaving behind trusted healthcare providers. Patients have repeatedly mentioned finding it difficult to establish a trusting relationship with their new healthcare providers for various reasons such as having to meet a different doctor at every appointment. Furthermore, it has been speculated that this can have a negative impact on patients’ adherence to their treatment, as they may opt to not attend their medical follow-ups. Our results offer support for this idea, showing that patients who perceive their healthcare providers as autonomy supportive also feel higher levels of autonomous motivation and higher feelings of perceived competence in the management of their condition. Finally, perceived competence was associated with higher levels of perceived adherence to treatment. These results are in line with Huang et al.’s (2011) suggestion of addressing patient-valued priorities and engaging patients in the self-management of their condition. Other studies have also reported on the importance of adolescent patients feeling self-efficacious (Loes van Staa et al., 2011) and on the impact self-efficacy can have on self-care and on clinical outcomes (Anderson & Wolpert, 2004). High levels of patients' self-efficacy have also been shown to be predictors of patients remaining in care once in ACC (Wojciechowski, Hurtig & Dorn, 2002). Similarly, our results illustrated the importance of patients feeling competent about managing their condition, with patients who remained in the study expressing higher feelings of competence in comparison to those who abandoned the study.

Limitations of the thesis

While the present work brings forth several contributions to the body of literature on transition, it is not without its limitations. Firstly, it is important to note that the empirical articles of the thesis are based on results obtained from patients who attended their medical appointment at Time 1 (prior to transfer). Those who did not show up could not be recruited. The results may thus be biased, in that patients who were reliable in attending their appointment in CCC may show higher levels of adherence to their healthcare regimen and generally feel more motivated to take care of their medical condition. In addition, it is important to point out that we found significant differences in the characteristics of patients who remained in the study and those who abandoned the study at the time of the follows-ups. For example, patients who remained in the study across time were found to be more preoccupied with good health and perceived themselves as more competent in the management of their medical condition. Although we cannot generalize the results obtained following the transfer to all patients, the differences found between patients who remained in the study and those who left are informative and may suggest that the latter patients experienced more difficulties in ACC.

Secondly, the small number of patients recruited in the diabetes and renal transplant clinics required us to combine the two patient groups, preventing us from obtaining information specific to each one of these medical conditions, which may or may not be different. However, it is important to note that numerous studies have pooled patient groups when conducting research on chronic conditions. Indeed, although every chronic condition has its particularities, many have similarities including requiring daily monitoring, medication, and regular medical visits. With respect to the control group used for comparisons, all participants were recruited from CEGEP institutions in contrast to the patient population, which represented students in institutions ranging from high school to university. The two groups were thus heterogeneous with respect to their educational background.

Thirdly, it is important to emphasize that the results were obtained via questionnaires and thus reflect patients' perception of their development and of their adherence to treatment. It is suggested that more objective formats of assessing these variables could have provided a clearer picture of what occurs following transfer to ACC. Furthermore, the association made between variables were made by means of correlations which prevents us from talking about causal relationships.

Practical implications of the thesis

The present thesis is relevant for clinical practice for both patients and healthcare providers. Firstly, the thesis is informative with respect to patients' feelings and concerns prior to and following transfer to ACC. Along with other studies, our results provide a picture of what patients require to feel prepared throughout their transition process. An emphasis is put on the preparation towards transition. While past studies have made recommendations such as the implementation of transition programs or young adult clinics to facilitate the transition process, the metasummary offered a series of recommendations that can easily be implemented in CCC environments to prepare patients. The use of open-ended questions is suggested in order to assess the meaning patients give to transition and encourage a positive outlook on this important event. In the same vein, the use of open-ended questions can help healthcare providers assess patients' expectations about the ACC environment and correct any misconception patients may have about the latter environment.

The results discussed in this thesis serve to highlight the importance of patients' readiness to transfer. Firstly, patients who feel prepared for the transfer also feel more competent to manage their medical condition. It is, however, important for healthcare practitioners to assess patients' readiness in a systematic way prior to the transfer. As shown in our study, feeling ready to transfer when one is still in CCC does not necessarily translate into perceived competence or adherence to treatment in ACC. Patients' misconceptions about ACC (for e.g., that it is not different from CCC) may lead them to report they feel ready to transfer. As such, informing patients of the differences they may encounter in ACC can be a way to prepare them for their transfer.

The findings presented also shed light on patients' identity development and QOL. In both respects, patients perceived themselves as developing similarly to their healthy peers. These findings are important as they reflect patients' perception of themselves as 'being normal' and corroborate their wishes for normalcy. Indeed, while adolescents with a chronic illness have to manage their condition on a daily basis, they strive for autonomy, as do their healthy counterparts. Fostering a sense of autonomy in patients throughout the transition process can assist them in managing their condition independently in ACC.

Lastly, the results of the thesis highlight the importance adolescent patients grant to the relationship they establish with healthcare providers, most notably with respect to trust. Studies on transition have often emphasized specific aspects of the process that require preparation (for e.g., ensuring patients are well informed with respect to their condition, finding a healthcare provider in ACC, transferring the medical file, etc.). However, while the importance of building a patient-provider relationship has been highlighted in several studies, it has not been a main focus of those studies. Our study corroborates past results, demonstrating that patients consider their relationship with their healthcare providers as of significant importance. The results also illustrate the positive impact a strong and trustful relationship can have on patients' satisfaction and adherence to treatment.

Recommendations for future research

Thus far, research studies have mainly focused on understanding patients' experience and feelings during the transition process as well as on obtaining patients' recommendations for making transition smoother. While the results we obtained corroborate many previous findings, the approach and the methodology adopted can set the stage for future research work.

The first recommendation lays in the methodology used in transition studies. While previous studies on transition are informative, it is believed that the use of a theoretical framework should be incorporated in future studies on transition. The use of theoretical frameworks can help researchers obtain a deeper understanding of the data collected. It is also useful in organizing data in a coherent model and helps with the translation of data into practical interventions (Gerrity, 1994). Furthermore, an emphasis should be placed on the use of a longitudinal methodology in future studies. While obtaining information on the moments that precede and follow the transfer of care, transition is a process and important associations can be made between the events that precede and those that follow the actual transfer. A systematic way of tracking patients following their transfer to ACC will allow for a better understanding of the reality of those who encounter difficulties in the new environment.

Furthermore, while the present work looked at the important variable of identity development in patients prior to their transfer to ACC, the impact of patients' identity status prior to their transfer was not investigated longitudinally. While previous research work has shown that identity can have an impact on the ways in which patients manage their condition (e.g., Luyckx et al., 2008), it is worth investigating whether a patient's identity status prior to the transfer to ACC impacts their adaptation to ACC.

Lastly, it is believed that the most important gap in the current transition of care literature is in the lack of research studies on transition programs. Indeed, researchers in the past two decades have placed significant emphasis on researching patients' transition experience in a descriptive fashion. Thus, an important body of literature exists on patients' recommendations for a smoother transition to ACC. The next step by researchers should be to assess the impact of patients' recommendations in a systematic way. Although it is impossible for every healthcare environment to set up transition programs or young adult clinics, there exist numerous recommendations that can be implemented and evaluated simply (e.g., informing patients on ACC practices).

Conclusion

Transition of care is a complex longitudinal process that has gained significant importance in the past few decades. The present work adds to the body of literature in this field by using a longitudinal methodology anchored in theoretical frameworks. The findings are informative with respect to important variables that impact the transition process at the individual and contextual levels. Future studies should assess the impact of the recommendations made using a longitudinal methodology.

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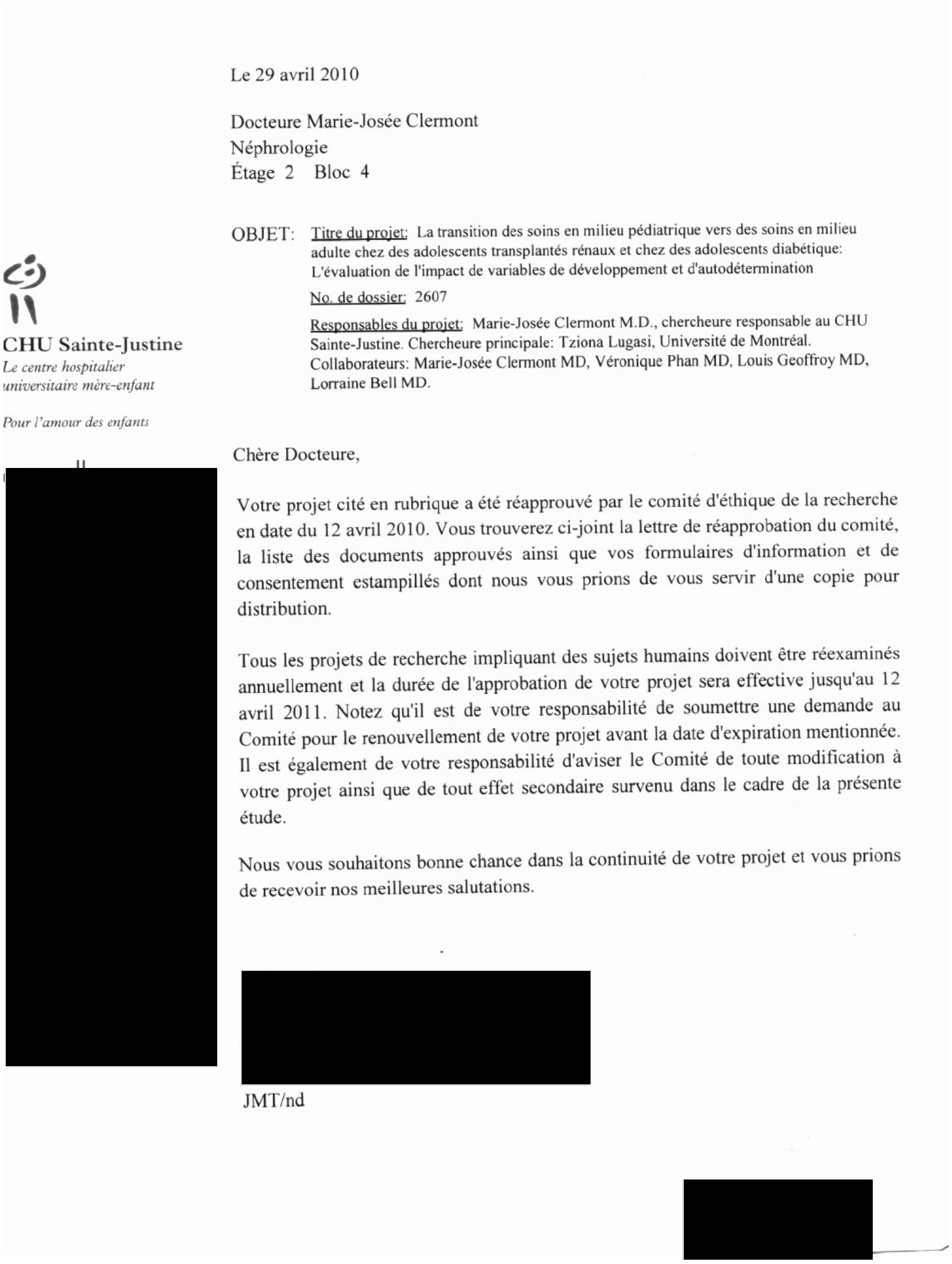
Annexe A

Approbation du comité éthique du CHU Sainte-Justine



CHU Sainte-Justine
Le centre hospitalier
universitaire mère-enfant

Pour l'amour des enfants

[redacted]

Le 29 avril 2010

Docteure Marie-Josée Clermont
Néphrologie
Étage 2 Bloc 4

OBJET: Titre du projet: La transition des soins en milieu pédiatrique vers des soins en milieu adulte chez des adolescents transplantés rénaux et chez des adolescents diabétique: L'évaluation de l'impact de variables de développement et d'autodétermination

No. de dossier: 2607

Responsables du projet: Marie-Josée Clermont M.D., chercheure responsable au CHU Sainte-Justine. Chercheure principale: Tziona Lugasi, Université de Montréal. Collaborateurs: Marie-Josée Clermont MD, Véronique Phan MD, Louis Geoffroy MD, Lorraine Bell MD.

Chère Docteure,

Votre projet cité en rubrique a été réapprouvé par le comité d'éthique de la recherche en date du 12 avril 2010. Vous trouverez ci-joint la lettre de réapprobation du comité, la liste des documents approuvés ainsi que vos formulaires d'information et de consentement estampillés dont nous vous prions de vous servir d'une copie pour distribution.

Tous les projets de recherche impliquant des sujets humains doivent être réexaminés annuellement et la durée de l'approbation de votre projet sera effective jusqu'au 12 avril 2011. Notez qu'il est de votre responsabilité de soumettre une demande au Comité pour le renouvellement de votre projet avant la date d'expiration mentionnée. Il est également de votre responsabilité d'aviser le Comité de toute modification à votre projet ainsi que de tout effet secondaire survenu dans le cadre de la présente étude.

Nous vous souhaitons bonne chance dans la continuité de votre projet et vous prions de recevoir nos meilleures salutations.

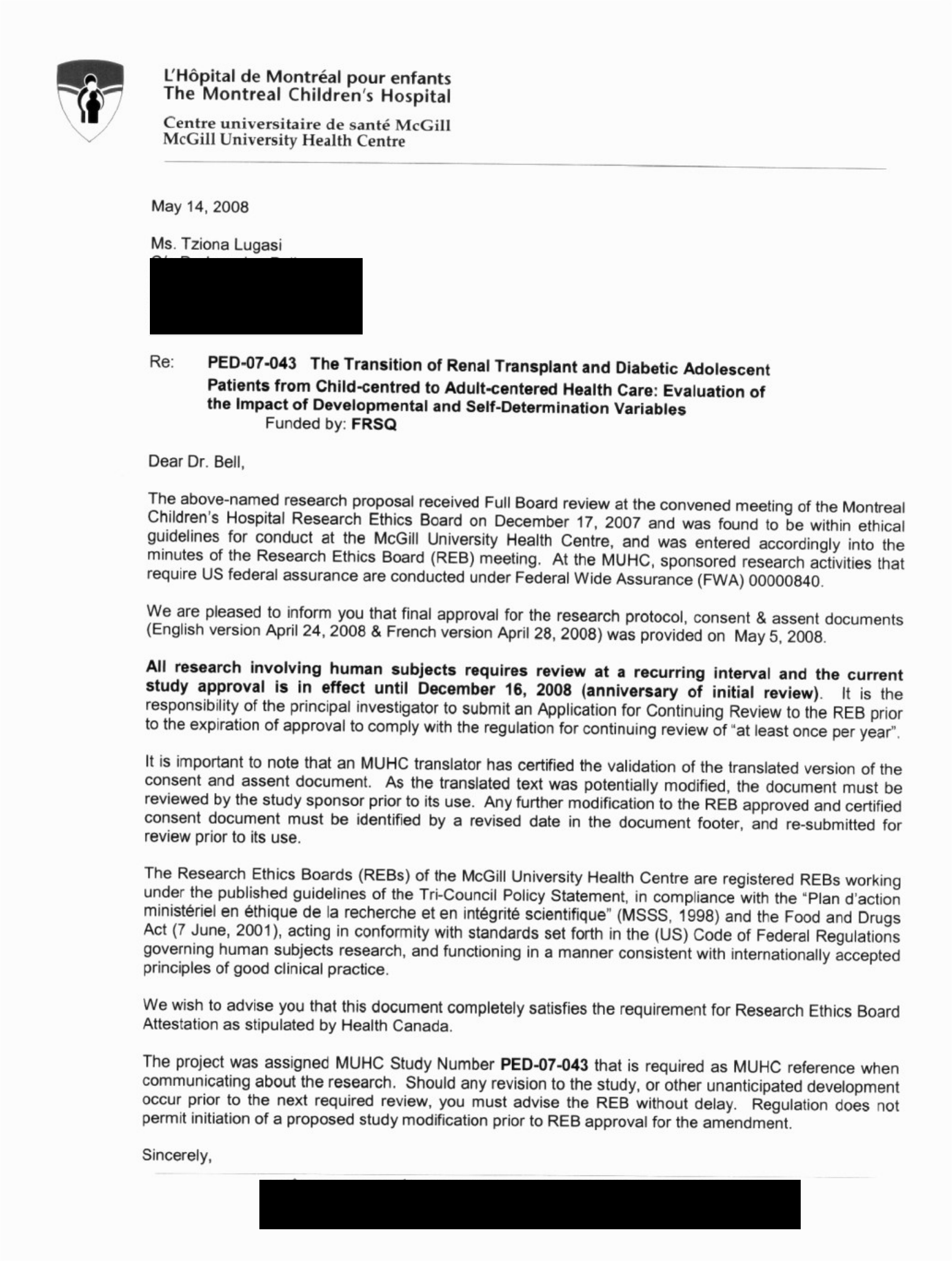
[redacted]

JMT/nd

[redacted]

Annexe B

Approbation du comité éthique du Montreal Children's Hospital



L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital

Centre universitaire de santé McGill
McGill University Health Centre

May 14, 2008

Ms. Tziona Lugasi
[redacted]

Re: **PED-07-043 The Transition of Renal Transplant and Diabetic Adolescent Patients from Child-centred to Adult-centered Health Care: Evaluation of the Impact of Developmental and Self-Determination Variables**
Funded by: **FRSQ**

Dear Dr. Bell,

The above-named research proposal received Full Board review at the convened meeting of the Montreal Children's Hospital Research Ethics Board on December 17, 2007 and was found to be within ethical guidelines for conduct at the McGill University Health Centre, and was entered accordingly into the minutes of the Research Ethics Board (REB) meeting. At the MUHC, sponsored research activities that require US federal assurance are conducted under Federal Wide Assurance (FWA) 00000840.

We are pleased to inform you that final approval for the research protocol, consent & assent documents (English version April 24, 2008 & French version April 28, 2008) was provided on May 5, 2008.

All research involving human subjects requires review at a recurring interval and the current study approval is in effect until December 16, 2008 (anniversary of initial review). It is the responsibility of the principal investigator to submit an Application for Continuing Review to the REB prior to the expiration of approval to comply with the regulation for continuing review of "at least once per year".

It is important to note that an MUHC translator has certified the validation of the translated version of the consent and assent document. As the translated text was potentially modified, the document must be reviewed by the study sponsor prior to its use. Any further modification to the REB approved and certified consent document must be identified by a revised date in the document footer, and re-submitted for review prior to its use.

The Research Ethics Boards (REBs) of the McGill University Health Centre are registered REBs working under the published guidelines of the Tri-Council Policy Statement, in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, 1998) and the Food and Drugs Act (7 June, 2001), acting in conformity with standards set forth in the (US) Code of Federal Regulations governing human subjects research, and functioning in a manner consistent with internationally accepted principles of good clinical practice.

We wish to advise you that this document completely satisfies the requirement for Research Ethics Board Attestation as stipulated by Health Canada.

The project was assigned MUHC Study Number **PED-07-043** that is required as MUHC reference when communicating about the research. Should any revision to the study, or other unanticipated development occur prior to the next required review, you must advise the REB without delay. Regulation does not permit initiation of a proposed study modification prior to REB approval for the amendment.

Sincerely,

[redacted]

Annexe C

Approbation du comité éthique du Manitoba Institute of Child Health

BANNATYNE CAMPUS
Research Ethics Boards

UNIVERSITY OF MANITOBA

[redacted]

APPROVAL FORM

Principal Investigator: Dr. T. Blydt-Hansen

Ethics Reference Number: H2008:291
Date of Approval: October 20, 2011
Date of Expiry: October 20, 2012

Protocol Title: The Transition of Renal Transplant and Diabetic Adolescent Patients from child-centered to adult-centered health care: Evaluation of the impact of developmental and self-determination variables

The following is/are approved for use:

- **Annual Approval**
- **Research Participant Information and Consent Form, Version 1 dated October 16, 2008**

The above was approved by Dr. John Arnett, Ph.D., C. Psych., Chair, Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your submission dated September 26, 2011. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the *Food and Drug Regulations of Canada.*

This approval is valid until the expiry date only. A study status report must be submitted annually and must accompany your request for re-approval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

This approval is for the ethics of human use only. For the logistics of performing the study, approval must be sought from the relevant institution, if required.

Sincerely yours,

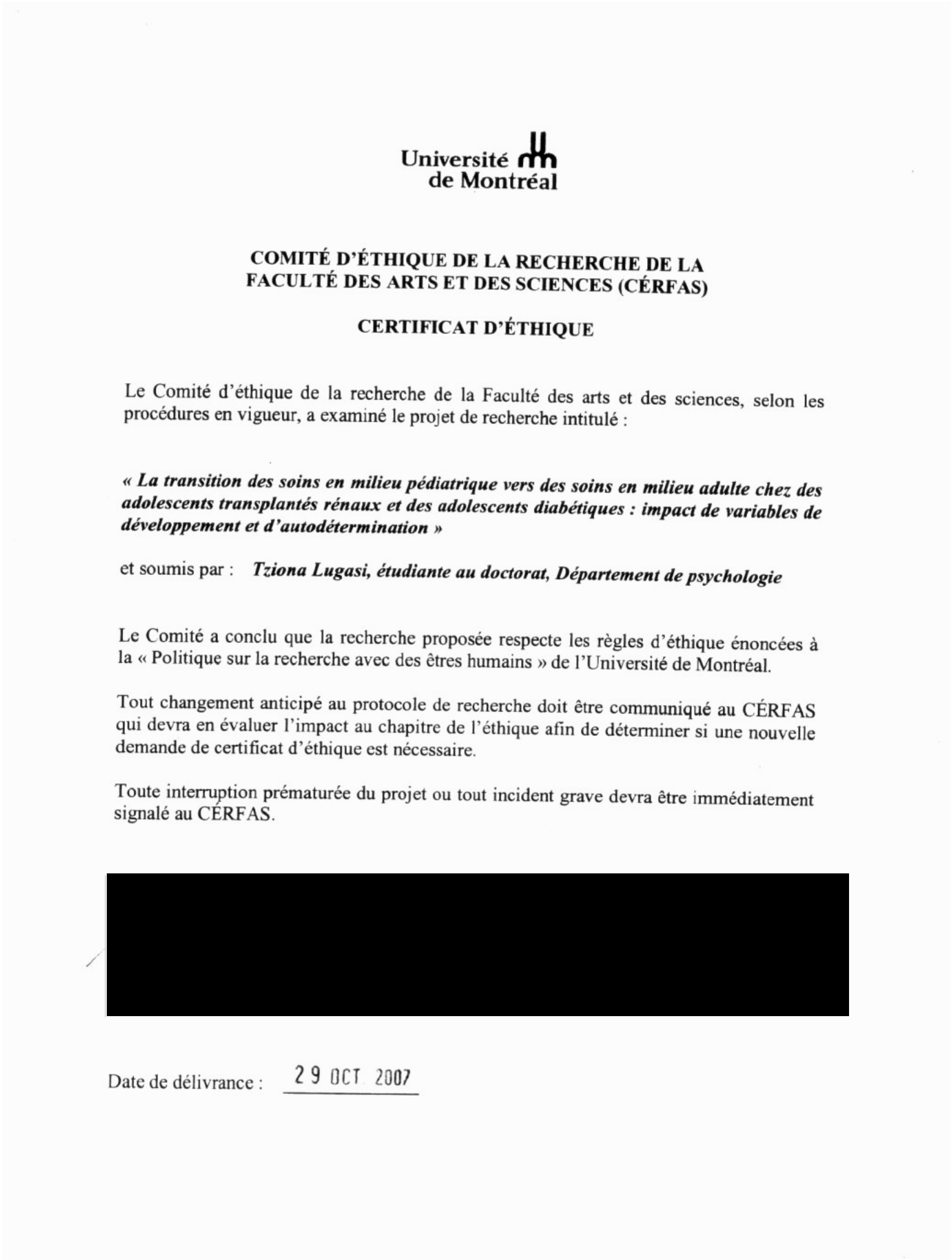
[redacted]

[redacted]

[redacted]

Annexe D

Approbation du comité éthique de l'Université de Montréal



Université de Montréal

COMITÉ D'ÉTHIQUE DE LA RECHERCHE DE LA FACULTÉ DES ARTS ET DES SCIENCES (CÉRFAS)

CERTIFICAT D'ÉTHIQUE

Le Comité d'éthique de la recherche de la Faculté des arts et des sciences, selon les procédures en vigueur, a examiné le projet de recherche intitulé :

« La transition des soins en milieu pédiatrique vers des soins en milieu adulte chez des adolescents transplantés rénaux et des adolescents diabétiques : impact de variables de développement et d'autodétermination »

et soumis par : ***Tziona Lugasi, étudiante au doctorat, Département de psychologie***

Le Comité a conclu que la recherche proposée respecte les règles d'éthique énoncées à la « Politique sur la recherche avec des êtres humains » de l'Université de Montréal.

Tout changement anticipé au protocole de recherche doit être communiqué au CÉRFAS qui devra en évaluer l'impact au chapitre de l'éthique afin de déterminer si une nouvelle demande de certificat d'éthique est nécessaire.

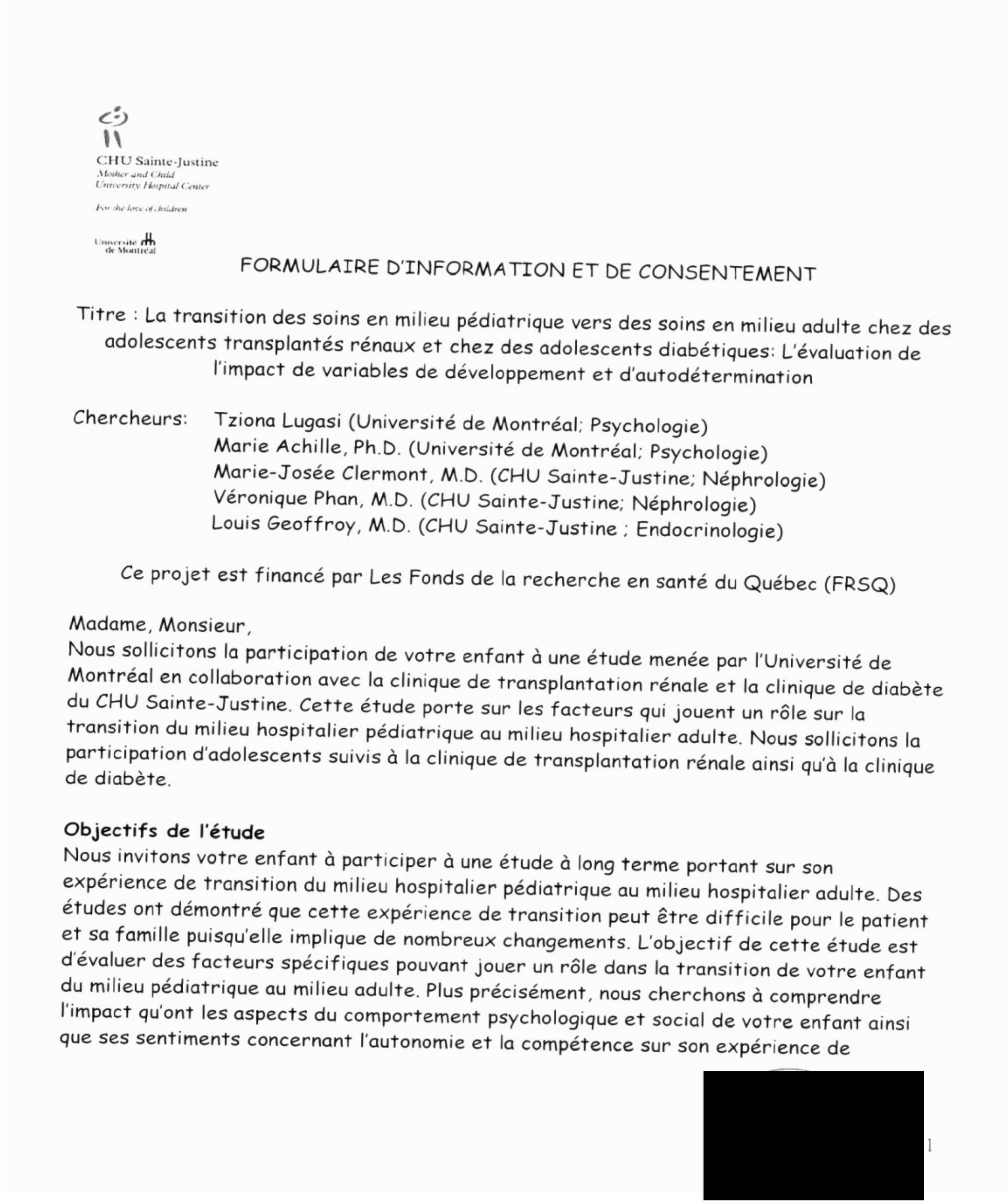
Toute interruption prématurée du projet ou tout incident grave devra être immédiatement signalé au CÉRFAS.

[redacted]

Date de délivrance : 29 OCT 2007

ANNEXE E

Formulaire de consentement du CHU Sainte-Justine



CHU Sainte-Justine
Mother and Child
University Hospital Center
For the love of children

Université de Montréal

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

Titre : La transition des soins en milieu pédiatrique vers des soins en milieu adulte chez des adolescents transplantés rénaux et chez des adolescents diabétiques: L'évaluation de l'impact de variables de développement et d'autodétermination

Chercheurs: Tziona Lugasi (Université de Montréal; Psychologie)
Marie Achille, Ph.D. (Université de Montréal; Psychologie)
Marie-Josée Clermont, M.D. (CHU Sainte-Justine; Néphrologie)
Véronique Phan, M.D. (CHU Sainte-Justine; Néphrologie)
Louis Geoffroy, M.D. (CHU Sainte-Justine ; Endocrinologie)

Ce projet est financé par Les Fonds de la recherche en santé du Québec (FRSQ)

Madame, Monsieur,
Nous sollicitons la participation de votre enfant à une étude menée par l'Université de Montréal en collaboration avec la clinique de transplantation rénale et la clinique de diabète du CHU Sainte-Justine. Cette étude porte sur les facteurs qui jouent un rôle sur la transition du milieu hospitalier pédiatrique au milieu hospitalier adulte. Nous sollicitons la participation d'adolescents suivis à la clinique de transplantation rénale ainsi qu'à la clinique de diabète.

Objectifs de l'étude
Nous invitons votre enfant à participer à une étude à long terme portant sur son expérience de transition du milieu hospitalier pédiatrique au milieu hospitalier adulte. Des études ont démontré que cette expérience de transition peut être difficile pour le patient et sa famille puisqu'elle implique de nombreux changements. L'objectif de cette étude est d'évaluer des facteurs spécifiques pouvant jouer un rôle dans la transition de votre enfant du milieu pédiatrique au milieu adulte. Plus précisément, nous cherchons à comprendre l'impact qu'ont les aspects du comportement psychologique et social de votre enfant ainsi que ses sentiments concernant l'autonomie et la compétence sur son expérience de

[redacted]

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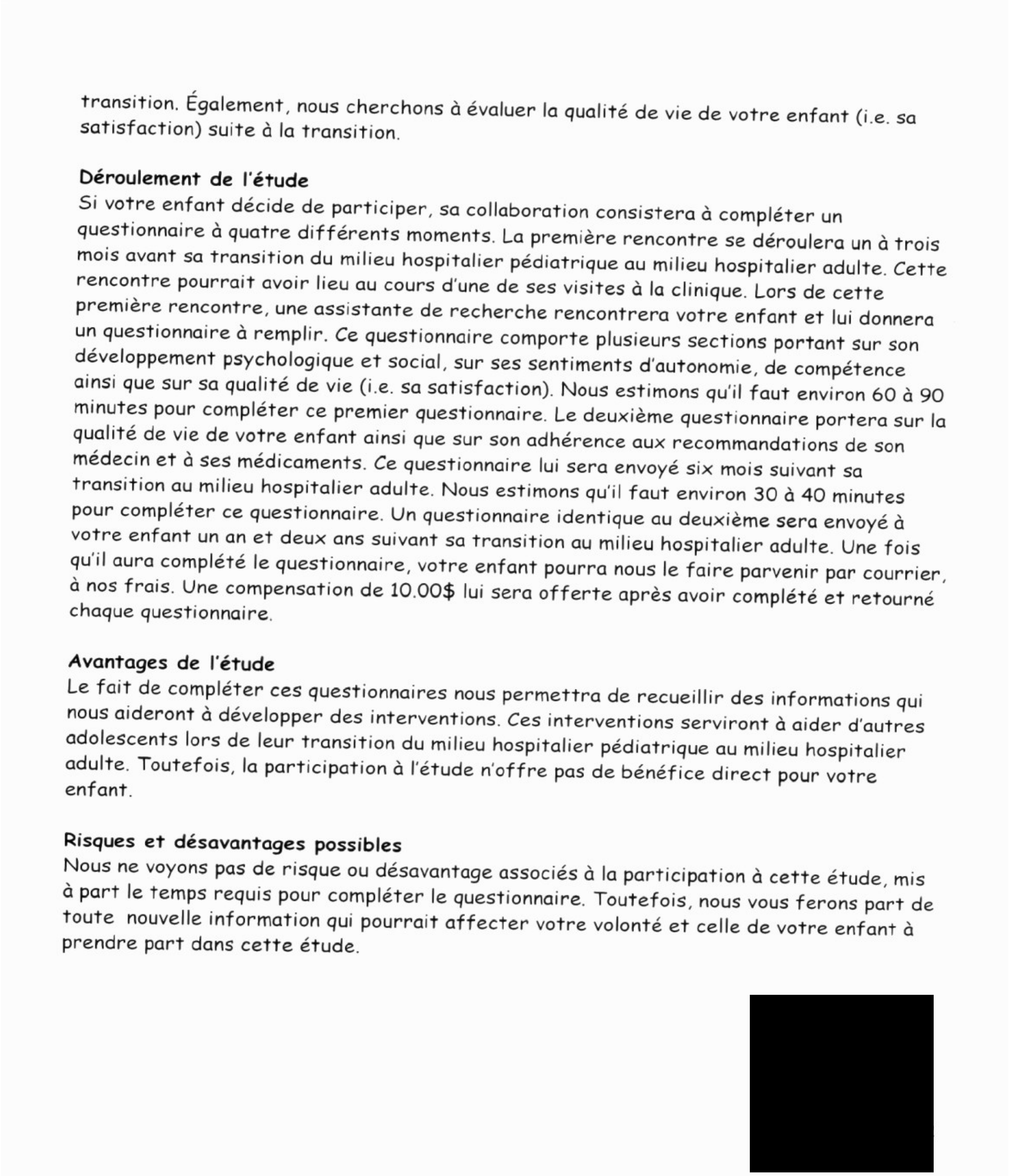


transition. Également, nous cherchons à évaluer la qualité de vie de votre enfant (i.e. sa satisfaction) suite à la transition.

Déroulement de l'étude

Si votre enfant décide de participer, sa collaboration consistera à compléter un questionnaire à quatre différents moments. La première rencontre se déroulera un à trois mois avant sa transition du milieu hospitalier pédiatrique au milieu hospitalier adulte. Cette rencontre pourrait avoir lieu au cours d'une de ses visites à la clinique. Lors de cette première rencontre, une assistante de recherche rencontrera votre enfant et lui donnera un questionnaire à remplir. Ce questionnaire comporte plusieurs sections portant sur son développement psychologique et social, sur ses sentiments d'autonomie, de compétence ainsi que sur sa qualité de vie (i.e. sa satisfaction). Nous estimons qu'il faut environ 60 à 90 minutes pour compléter ce premier questionnaire. Le deuxième questionnaire portera sur la qualité de vie de votre enfant ainsi que sur son adhérence aux recommandations de son médecin et à ses médicaments. Ce questionnaire lui sera envoyé six mois suivant sa transition au milieu hospitalier adulte. Nous estimons qu'il faut environ 30 à 40 minutes pour compléter ce questionnaire. Un questionnaire identique au deuxième sera envoyé à votre enfant un an et deux ans suivant sa transition au milieu hospitalier adulte. Une fois qu'il aura complété le questionnaire, votre enfant pourra nous le faire parvenir par courrier, à nos frais. Une compensation de 10.00$ lui sera offerte après avoir complété et retourné chaque questionnaire.

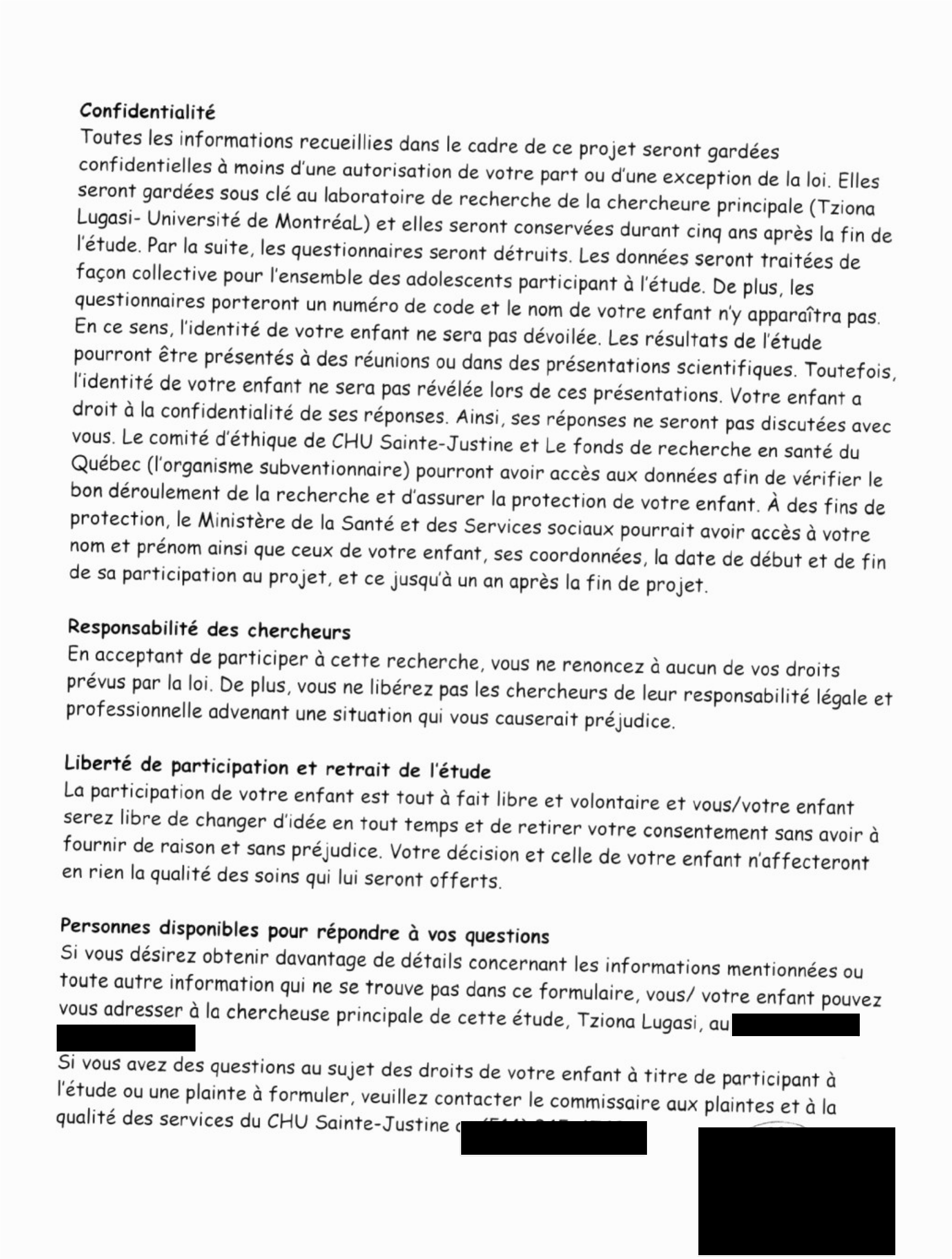
Avantages de l'étude

Le fait de compléter ces questionnaires nous permettra de recueillir des informations qui nous aideront à développer des interventions. Ces interventions serviront à aider d'autres adolescents lors de leur transition du milieu hospitalier pédiatrique au milieu hospitalier adulte. Toutefois, la participation à l'étude n'offre pas de bénéfice direct pour votre enfant.

Risques et désavantages possibles

Nous ne voyons pas de risque ou désavantage associés à la participation à cette étude, mis à part le temps requis pour compléter le questionnaire. Toutefois, nous vous ferons part de toute nouvelle information qui pourrait affecter votre volonté et celle de votre enfant à prendre part dans cette étude.

[redacted]



Confidentialité

Toutes les informations recueillies dans le cadre de ce projet seront gardées confidentielles à moins d'une autorisation de votre part ou d'une exception de la loi. Elles seront gardées sous clé au laboratoire de recherche de la chercheure principale (Tziona Lugasi- Université de MontréaL) et elles seront conservées durant cinq ans après la fin de l'étude. Par la suite, les questionnaires seront détruits. Les données seront traitées de façon collective pour l'ensemble des adolescents participant à l'étude. De plus, les questionnaires porteront un numéro de code et le nom de votre enfant n'y apparaîtra pas. En ce sens, l'identité de votre enfant ne sera pas dévoilée. Les résultats de l'étude pourront être présentés à des réunions ou dans des présentations scientifiques. Toutefois, l'identité de votre enfant ne sera pas révélée lors de ces présentations. Votre enfant a droit à la confidentialité de ses réponses. Ainsi, ses réponses ne seront pas discutées avec vous. Le comité d'éthique de CHU Sainte-Justine et Le fonds de recherche en santé du Québec (l'organisme subventionnaire) pourront avoir accès aux données afin de vérifier le bon déroulement de la recherche et d'assurer la protection de votre enfant. À des fins de protection, le Ministère de la Santé et des Services sociaux pourrait avoir accès à votre nom et prénom ainsi que ceux de votre enfant, ses coordonnées, la date de début et de fin de sa participation au projet, et ce jusqu'à un an après la fin de projet.

Responsabilité des chercheurs

En acceptant de participer à cette recherche, vous ne renoncez à aucun de vos droits prévus par la loi. De plus, vous ne libérez pas les chercheurs de leur responsabilité légale et professionnelle advenant une situation qui vous causerait préjudice.

Liberté de participation et retrait de l'étude

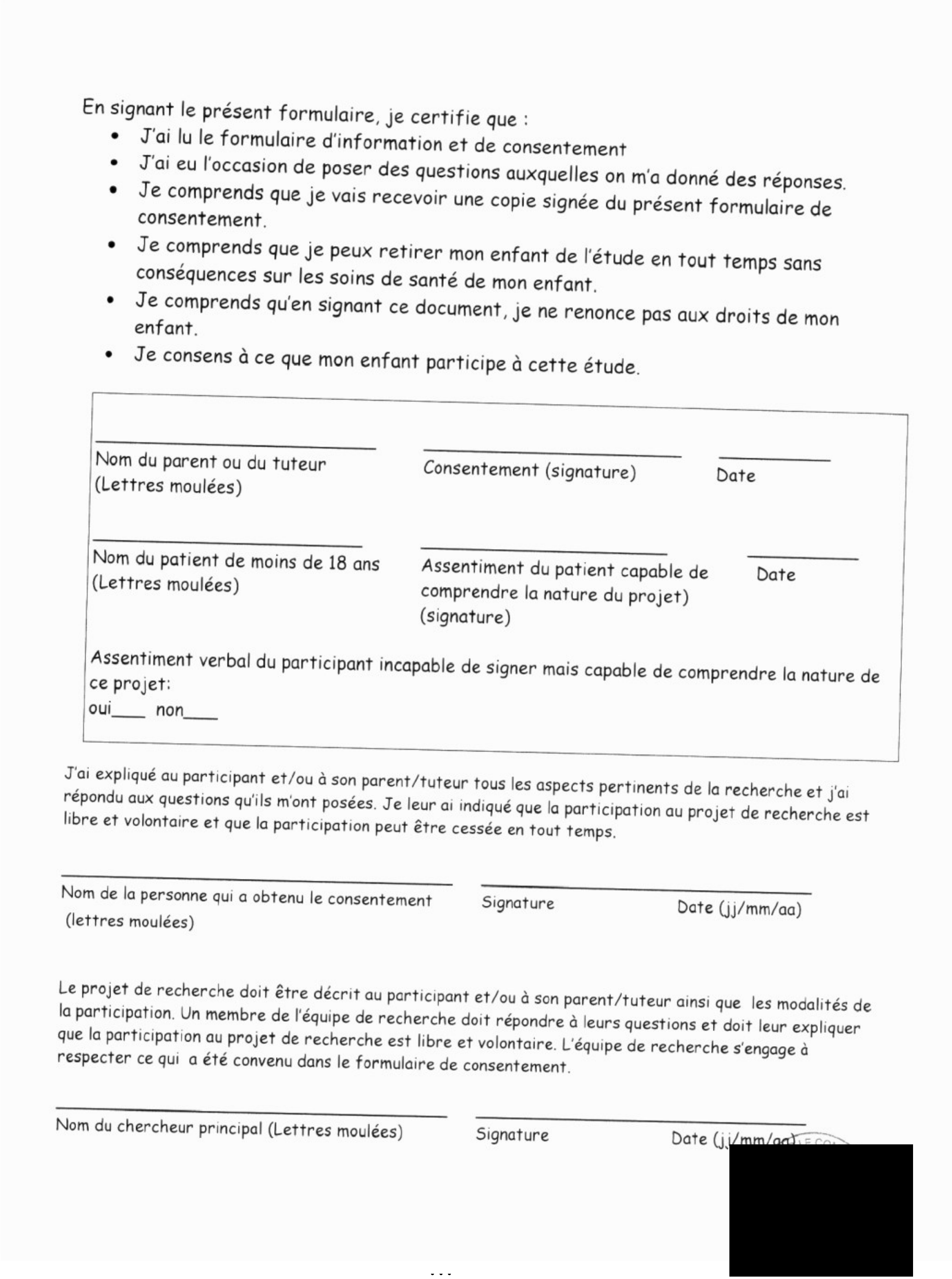
La participation de votre enfant est tout à fait libre et volontaire et vous/votre enfant serez libre de changer d'idée en tout temps et de retirer votre consentement sans avoir à fournir de raison et sans préjudice. Votre décision et celle de votre enfant n'affecteront en rien la qualité des soins qui lui seront offerts.

Personnes disponibles pour répondre à vos questions

Si vous désirez obtenir davantage de détails concernant les informations mentionnées ou toute autre information qui ne se trouve pas dans ce formulaire, vous/ votre enfant pouvez vous adresser à la chercheuse principale de cette étude, Tziona Lugasi, au [redacted]

Si vous avez des questions au sujet des droits de votre enfant à titre de participant à l'étude ou une plainte à formuler, veuillez contacter le commissaire aux plaintes et à la qualité des services du CHU Sainte-Justine [redacted]

[redacted]



En signant le présent formulaire, je certifie que :

- J'ai lu le formulaire d'information et de consentement
- J'ai eu l'occasion de poser des questions auxquelles on m'a donné des réponses.
- Je comprends que je vais recevoir une copie signée du présent formulaire de consentement.
- Je comprends que je peux retirer mon enfant de l'étude en tout temps sans conséquences sur les soins de santé de mon enfant.
- Je comprends qu'en signant ce document, je ne renonce pas aux droits de mon enfant.
- Je consens à ce que mon enfant participe à cette étude.

Nom du parent ou du tuteur (Lettres moulées) — Consentement (signature) — Date

Nom du patient de moins de 18 ans (Lettres moulées) — Assentiment du patient capable de comprendre la nature du projet) (signature) — Date

Assentiment verbal du participant incapable de signer mais capable de comprendre la nature de ce projet:

oui___ non___

J'ai expliqué au participant et/ou à son parent/tuteur tous les aspects pertinents de la recherche et j'ai répondu aux questions qu'ils m'ont posées. Je leur ai indiqué que la participation au projet de recherche est libre et volontaire et que la participation peut être cessée en tout temps.

Nom de la personne qui a obtenu le consentement (lettres moulées) — Signature — Date (jj/mm/aa)

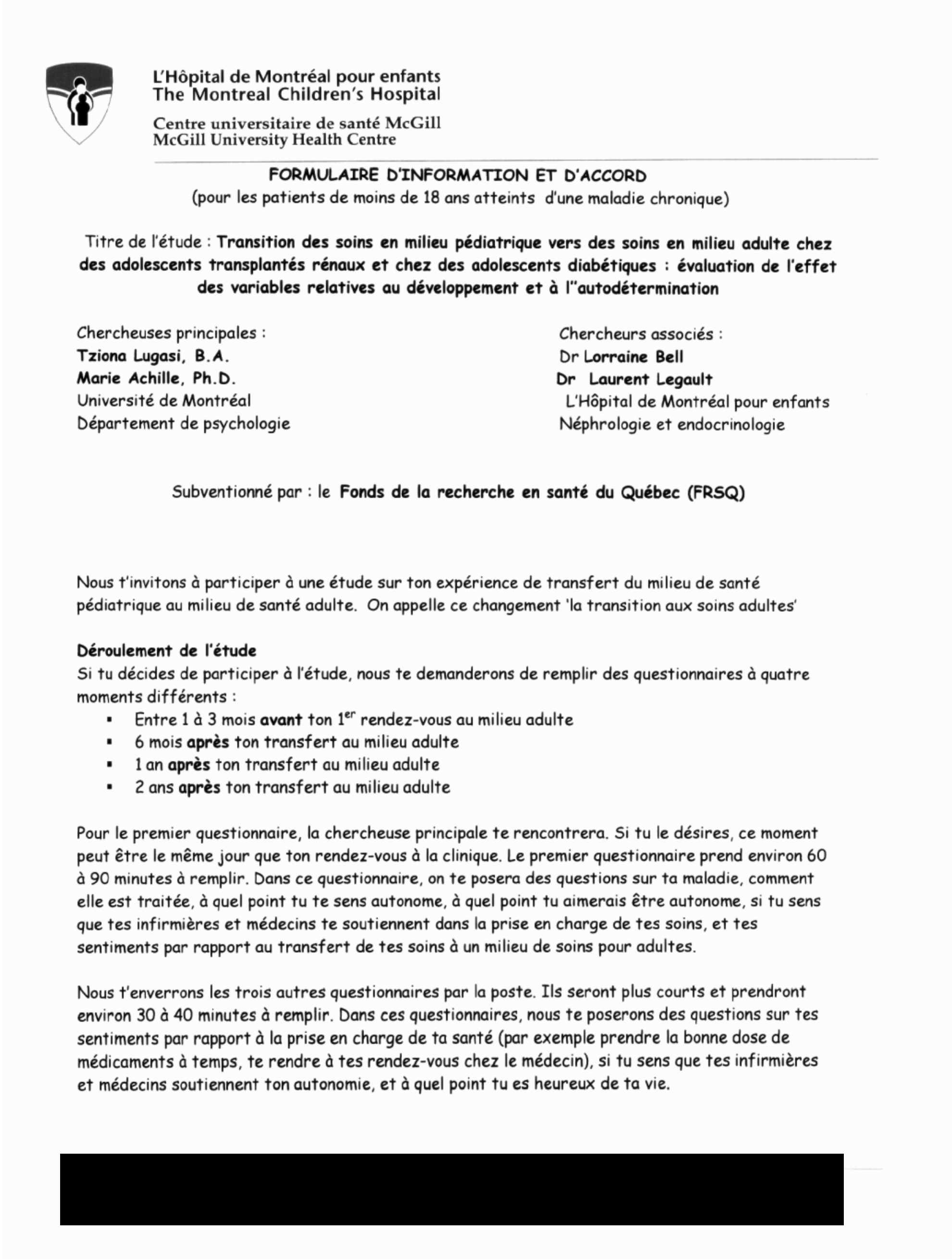
Le projet de recherche doit être décrit au participant et/ou à son parent/tuteur ainsi que les modalités de la participation. Un membre de l'équipe de recherche doit répondre à leurs questions et doit leur expliquer que la participation au projet de recherche est libre et volontaire. L'équipe de recherche s'engage à respecter ce qui a été convenu dans le formulaire de consentement.

Nom du chercheur principal (Lettres moulées) — Signature — Date (jj/mm/aa)

[redacted]

ANNEXE F

Formulaires de consentement du Montreal Children's Hospital



L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

FORMULAIRE D'INFORMATION ET D'ACCORD

(pour les patients de moins de 18 ans atteints d'une maladie chronique)

Titre de l'étude : **Transition des soins en milieu pédiatrique vers des soins en milieu adulte chez des adolescents transplantés rénaux et chez des adolescents diabétiques : évaluation de l'effet des variables relatives au développement et à l''autodétermination**

Chercheuses principales :	Chercheurs associés :
Tziona Lugasi, B.A.	Dr **Lorraine Bell**
Marie Achille, Ph.D.	**Dr Laurent Legault**
Université de Montréal	L'Hôpital de Montréal pour enfants
Département de psychologie	Néphrologie et endocrinologie

Subventionné par : le **Fonds de la recherche en santé du Québec (FRSQ)**

Nous t'invitons à participer à une étude sur ton expérience de transfert du milieu de santé pédiatrique au milieu de santé adulte. On appelle ce changement 'la transition aux soins adultes'

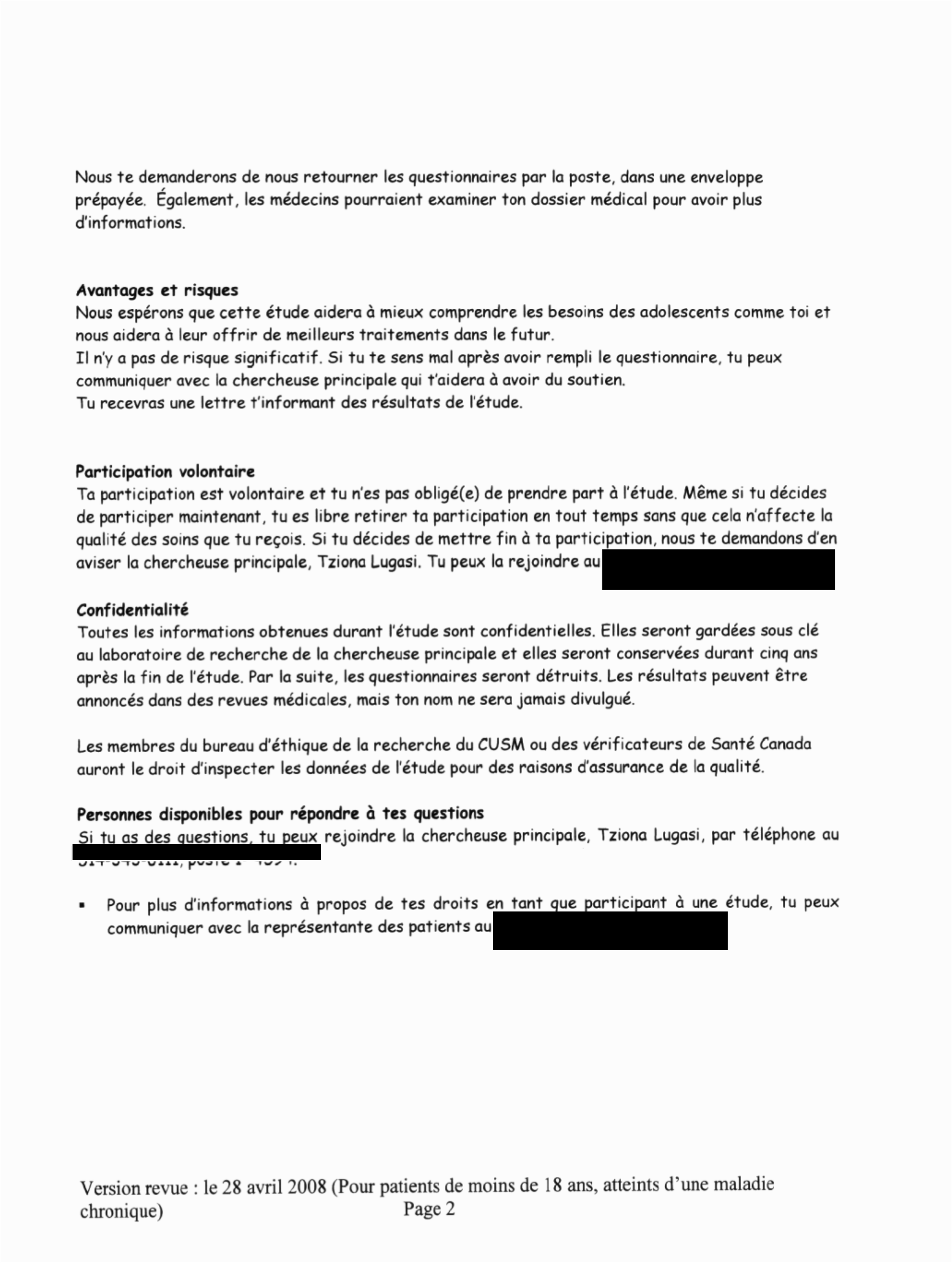
Déroulement de l'étude
Si tu décides de participer à l'étude, nous te demanderons de remplir des questionnaires à quatre moments différents :

- Entre 1 à 3 mois **avant** ton 1^er^ rendez-vous au milieu adulte
- 6 mois **après** ton transfert au milieu adulte
- 1 an **après** ton transfert au milieu adulte
- 2 ans **après** ton transfert au milieu adulte

Pour le premier questionnaire, la chercheuse principale te rencontrera. Si tu le désires, ce moment peut être le même jour que ton rendez-vous à la clinique. Le premier questionnaire prend environ 60 à 90 minutes à remplir. Dans ce questionnaire, on te posera des questions sur ta maladie, comment elle est traitée, à quel point tu te sens autonome, à quel point tu aimerais être autonome, si tu sens que tes infirmières et médecins te soutiennent dans la prise en charge de tes soins, et tes sentiments par rapport au transfert de tes soins à un milieu de soins pour adultes.

Nous t'enverrons les trois autres questionnaires par la poste. Ils seront plus courts et prendront environ 30 à 40 minutes à remplir. Dans ces questionnaires, nous te poserons des questions sur tes sentiments par rapport à la prise en charge de ta santé (par exemple prendre la bonne dose de médicaments à temps, te rendre à tes rendez-vous chez le médecin), si tu sens que tes infirmières et médecins soutiennent ton autonomie, et à quel point tu es heureux de ta vie.

[redacted]



Nous te demanderons de nous retourner les questionnaires par la poste, dans une enveloppe prépayée. Également, les médecins pourraient examiner ton dossier médical pour avoir plus d'informations.

Avantages et risques

Nous espérons que cette étude aidera à mieux comprendre les besoins des adolescents comme toi et nous aidera à leur offrir de meilleurs traitements dans le futur.

Il n'y a pas de risque significatif. Si tu te sens mal après avoir rempli le questionnaire, tu peux communiquer avec la chercheuse principale qui t'aidera à avoir du soutien.

Tu recevras une lettre t'informant des résultats de l'étude.

Participation volontaire

Ta participation est volontaire et tu n'es pas obligé(e) de prendre part à l'étude. Même si tu décides de participer maintenant, tu es libre retirer ta participation en tout temps sans que cela n'affecte la qualité des soins que tu reçois. Si tu décides de mettre fin à ta participation, nous te demandons d'en aviser la chercheuse principale, Tziona Lugasi. Tu peux la rejoindre au [redacted]

Confidentialité

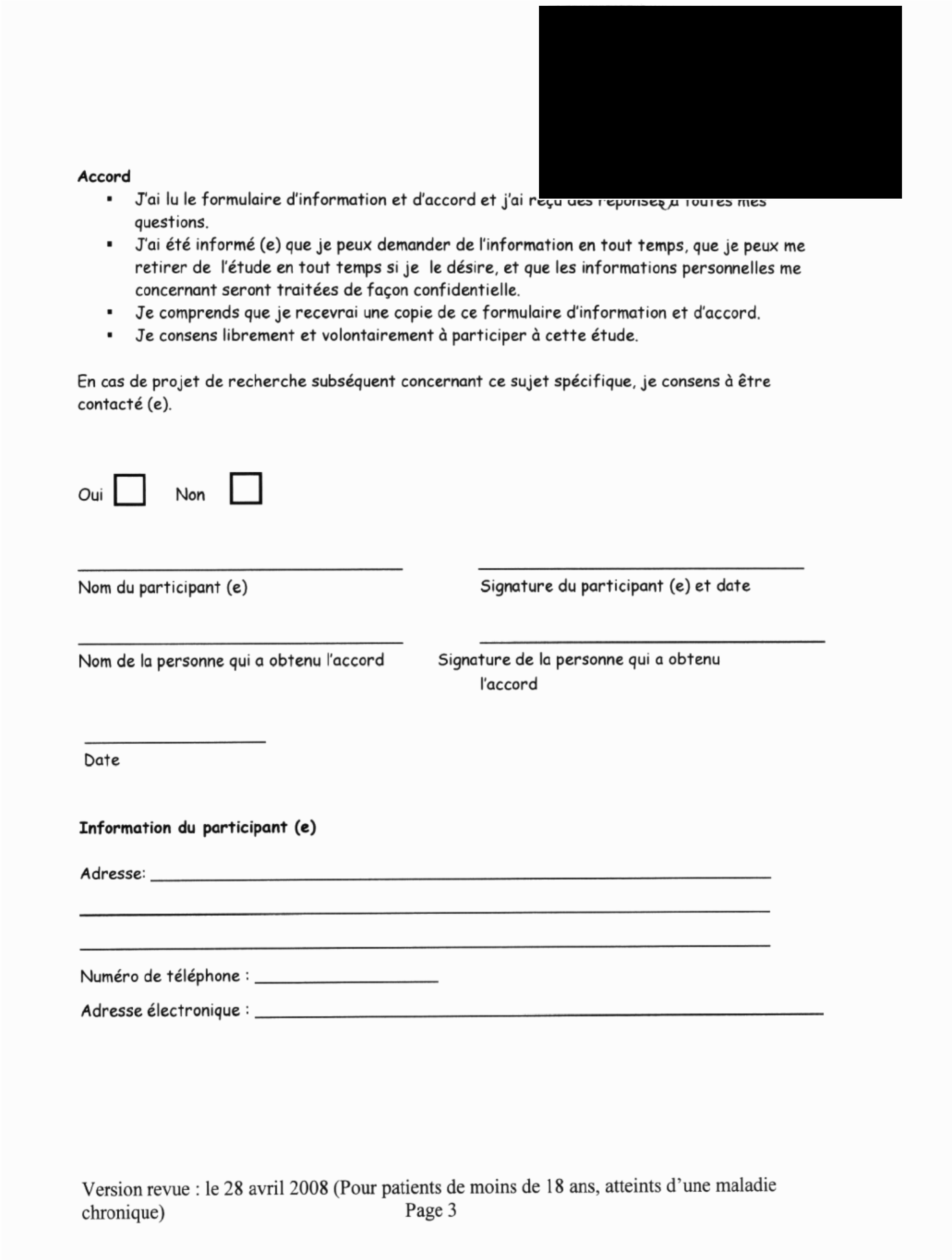
Toutes les informations obtenues durant l'étude sont confidentielles. Elles seront gardées sous clé au laboratoire de recherche de la chercheuse principale et elles seront conservées durant cinq ans après la fin de l'étude. Par la suite, les questionnaires seront détruits. Les résultats peuvent être annoncés dans des revues médicales, mais ton nom ne sera jamais divulgué.

Les membres du bureau d'éthique de la recherche du CUSM ou des vérificateurs de Santé Canada auront le droit d'inspecter les données de l'étude pour des raisons d'assurance de la qualité.

Personnes disponibles pour répondre à tes questions

Si tu as des questions, tu peux rejoindre la chercheuse principale, Tziona Lugasi, par téléphone au [redacted]

- Pour plus d'informations à propos de tes droits en tant que participant à une étude, tu peux communiquer avec la représentante des patients au [redacted]



Accord

- J'ai lu le formulaire d'information et d'accord et j'ai [redacted] questions.
- J'ai été informé (e) que je peux demander de l'information en tout temps, que je peux me retirer de l'étude en tout temps si je le désire, et que les informations personnelles me concernant seront traitées de façon confidentielle.
- Je comprends que je recevrai une copie de ce formulaire d'information et d'accord.
- Je consens librement et volontairement à participer à cette étude.

En cas de projet de recherche subséquent concernant ce sujet spécifique, je consens à être contacté (e).

Oui ☐ Non ☐

Nom du participant (e)	Signature du participant (e) et date
Nom de la personne qui a obtenu l'accord	Signature de la personne qui a obtenu l'accord

Date

Information du participant (e)

Adresse: ______________________________

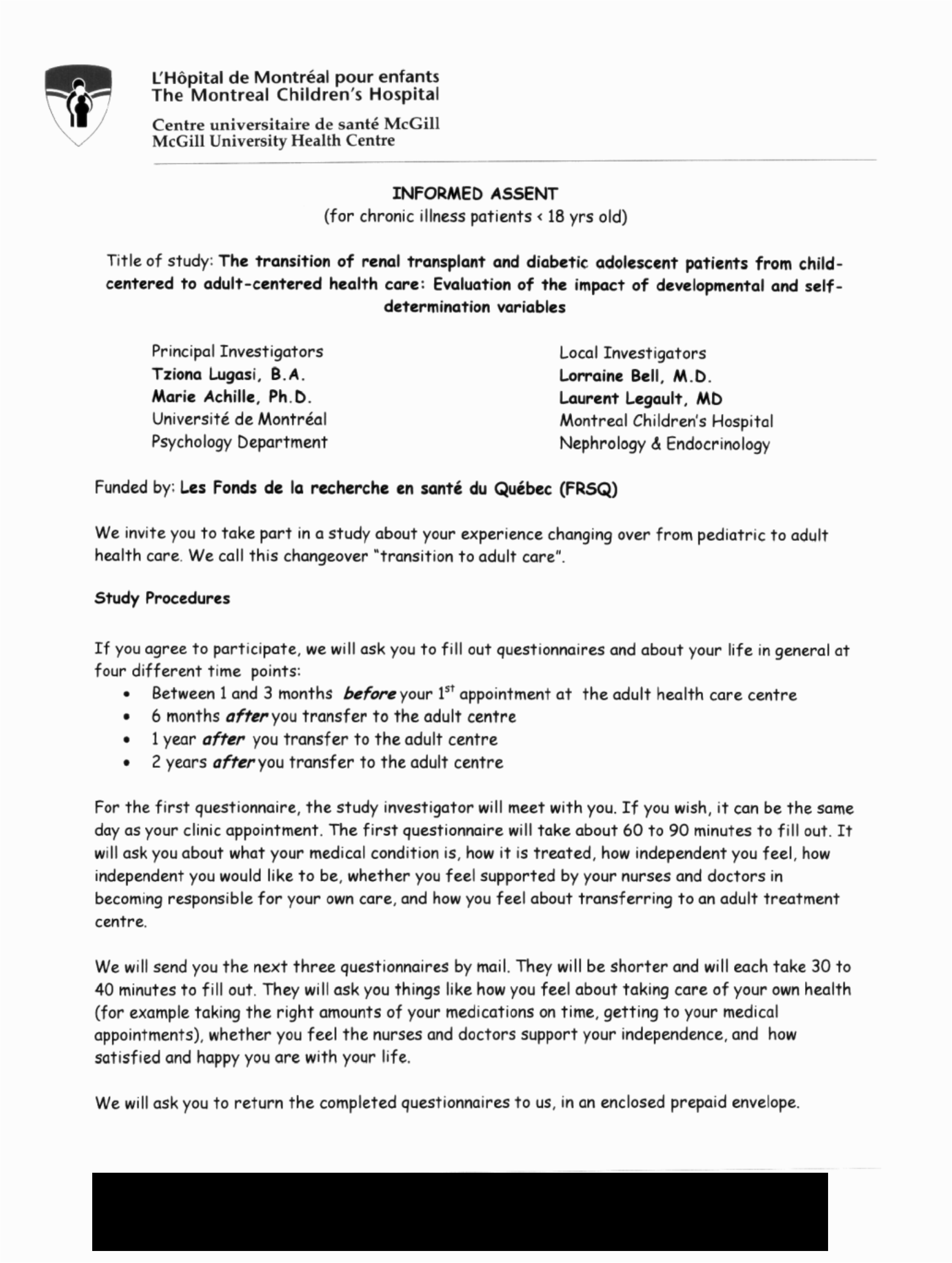
____

____

Numéro de téléphone : ______________

Adresse électronique : ______________________________

Version revue : le 28 avril 2008 (Pour patients de moins de 18 ans, atteints d'une maladie chronique)
Page 3



L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

INFORMED ASSENT

(for chronic illness patients < 18 yrs old)

Title of study: **The transition of renal transplant and diabetic adolescent patients from child-centered to adult-centered health care: Evaluation of the impact of developmental and self-determination variables**

Principal Investigators	Local Investigators
Tziona Lugasi, B.A.	**Lorraine Bell, M.D.**
Marie Achille, Ph.D.	**Laurent Legault, MD**
Université de Montréal	Montreal Children's Hospital
Psychology Department	Nephrology & Endocrinology

Funded by: **Les Fonds de la recherche en santé du Québec (FRSQ)**

We invite you to take part in a study about your experience changing over from pediatric to adult health care. We call this changeover "transition to adult care".

Study Procedures

If you agree to participate, we will ask you to fill out questionnaires and about your life in general at four different time points:

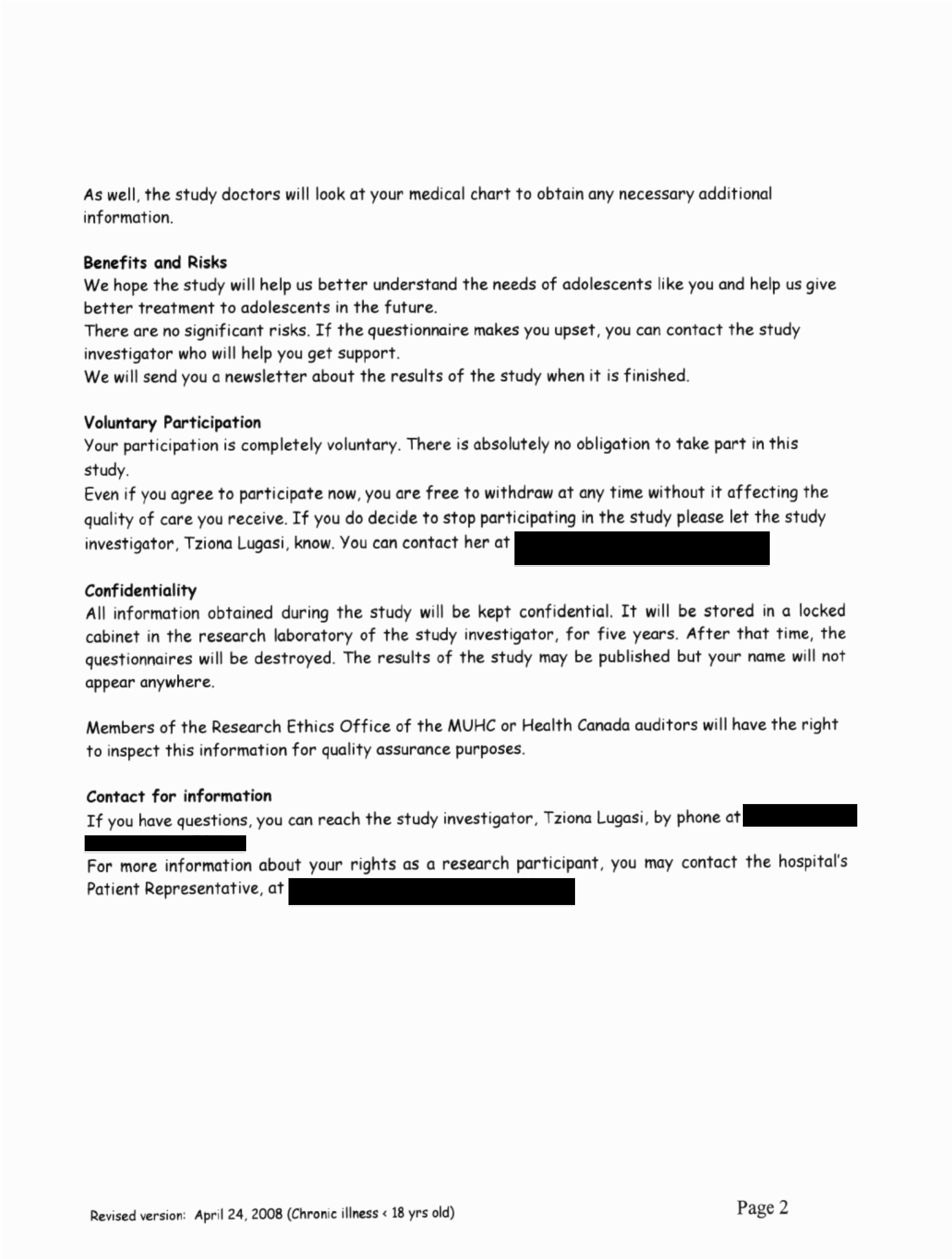
- Between 1 and 3 months ***before*** your 1st appointment at the adult health care centre
- 6 months ***after*** you transfer to the adult centre
- 1 year ***after*** you transfer to the adult centre
- 2 years ***after*** you transfer to the adult centre

For the first questionnaire, the study investigator will meet with you. If you wish, it can be the same day as your clinic appointment. The first questionnaire will take about 60 to 90 minutes to fill out. It will ask you about what your medical condition is, how it is treated, how independent you feel, how independent you would like to be, whether you feel supported by your nurses and doctors in becoming responsible for your own care, and how you feel about transferring to an adult treatment centre.

We will send you the next three questionnaires by mail. They will be shorter and will each take 30 to 40 minutes to fill out. They will ask you things like how you feel about taking care of your own health (for example taking the right amounts of your medications on time, getting to your medical appointments), whether you feel the nurses and doctors support your independence, and how satisfied and happy you are with your life.

We will ask you to return the completed questionnaires to us, in an enclosed prepaid envelope.

[redacted]



As well, the study doctors will look at your medical chart to obtain any necessary additional information.

Benefits and Risks

We hope the study will help us better understand the needs of adolescents like you and help us give better treatment to adolescents in the future.

There are no significant risks. If the questionnaire makes you upset, you can contact the study investigator who will help you get support.

We will send you a newsletter about the results of the study when it is finished.

Voluntary Participation

Your participation is completely voluntary. There is absolutely no obligation to take part in this study.

Even if you agree to participate now, you are free to withdraw at any time without it affecting the quality of care you receive. If you do decide to stop participating in the study please let the study investigator, Tziona Lugasi, know. You can contact her at [redacted]

Confidentiality

All information obtained during the study will be kept confidential. It will be stored in a locked cabinet in the research laboratory of the study investigator, for five years. After that time, the questionnaires will be destroyed. The results of the study may be published but your name will not appear anywhere.

Members of the Research Ethics Office of the MUHC or Health Canada auditors will have the right to inspect this information for quality assurance purposes.

Contact for information

If you have questions, you can reach the study investigator, Tziona Lugasi, by phone at [redacted]

For more information about your rights as a research participant, you may contact the hospital's Patient Representative, at [redacted]

Assent

I have read this Information and Assent Form and I have received answers to any questions I have asked.

I have been told that I may seek information at any time, that I am free to withdraw from the study any time I wish, and that my personal information will be kept confidential.

I understand I will receive a copy of this Information and Assent Form.

I freely and voluntarily assent to participate in this research study.

In case of subsequent research on this particular topic, I agree to be contacted.

Yes ☐ No ☐

Participant's name	Participant's signature and date
Name of the person who explained assent	Signature of the person who explained assent

Date

Participant's Contact Information

Address: ____________________

Phone Number: ____________________

E-mail address: ____________________

[redacted]

Revised version: April 24, 2008 (Chronic illness < 18 yrs old)

Page 3

L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

(pour les parents de patients ayant une maladie chronique)

Titre de l'étude: **Transition des soins en milieu pédiatrique vers des soins en milieu adulte chez des adolescents transplantés rénaux et chez des adolescents diabétiques : évaluation de l'effet des variables relatives au développement et à l''autodétermination**

Chercheuses principales :	Chercheurs associés :
Tziona Lugasi, B.A.	Dr **Lorraine Bell**
Marie Achille, Ph.D.	**Dr Laurent Legault**
Université de Montréal	L'Hôpital de Montréal pour enfants
Département de psychologie	Néphrologie et endocrinologie

Subventionné par: **Les Fonds de la recherche en santé du Québec (FRSQ)**

Nous invitons votre enfant à participer à une étude sur son expérience de transfert du milieu de santé pédiatrique au milieu de santé adulte. On appelle ce changement 'la transition aux soins adultes'

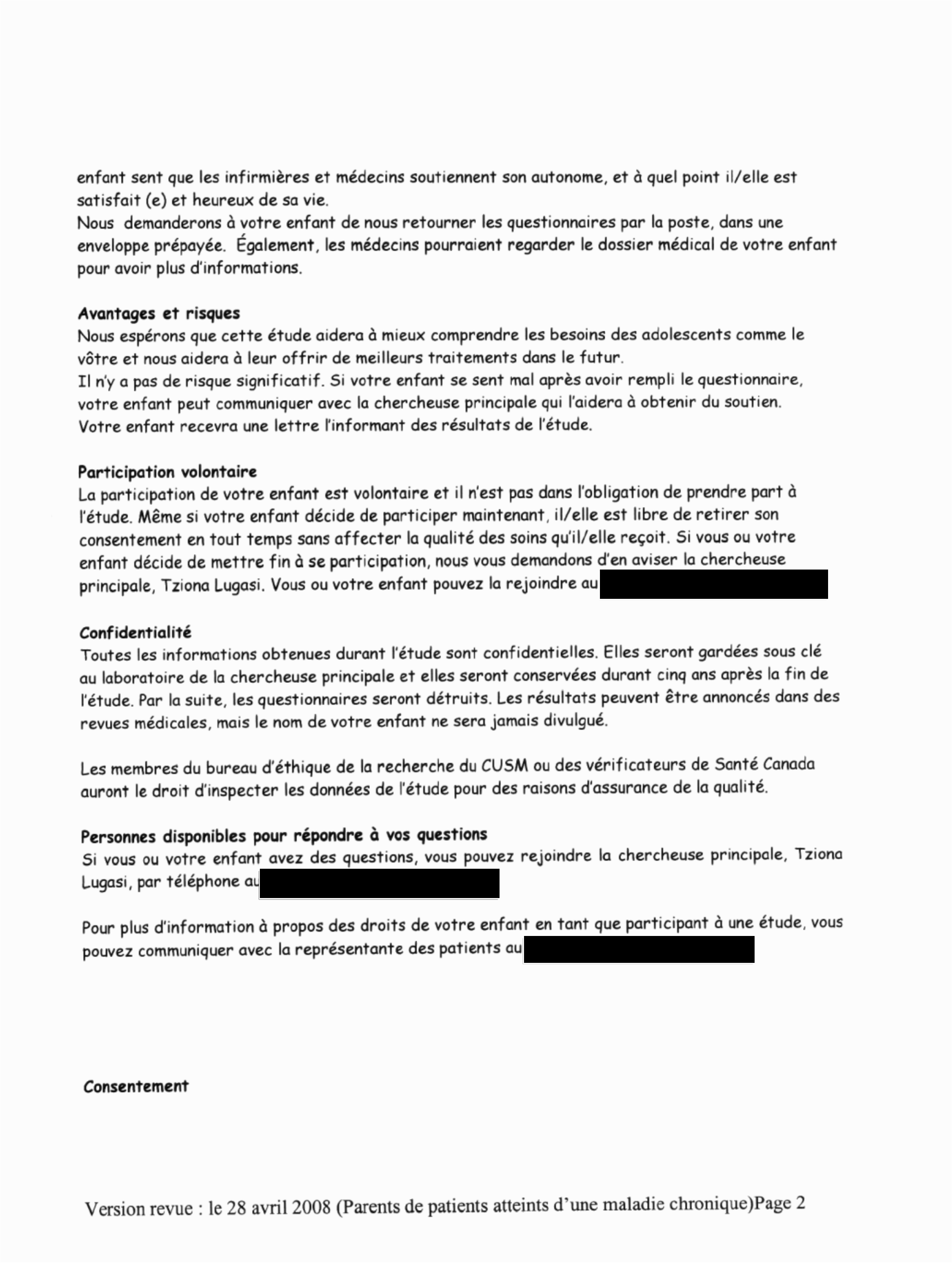
Déroulement de l'étude
Si votre enfant participe à l'étude, nous lui demanderons de remplir des questionnaires à quatre moments différents :

- Entre 1 à 3 mois **avant** son 1er rendez-vous au milieu adulte
- 6 mois **après** son transfert au milieu adulte
- 1 an **après** son transfert au milieu adulte
- 2 ans **après** son transfert au milieu adulte

Pour le premier questionnaire, la chercheuse principale rencontrera votre enfant pour l'aider à le remplir. Si vous et votre enfant le désirez, ce moment peut être le même jour de son rendez-vous à la clinique. Dans le premier questionnaire, nous lui poserons des questions sur sa maladie, comment celle-ci est traitée, à quel point votre enfant se sent autonome et à quel point il aimerait être autonome, s' il sent que les infirmières et médecins soutiennent son autonomie, et comment se sent-il par rapport à son transfert à un milieu de soins pour adultes.

Nous enverrons à votre enfant les trois autres questionnaires par la poste. Ils seront plus courts et prendront environ 30 à 40 minutes à remplir. Dans ces questionnaires, nous poserons à votre enfant des questions sur ses sentiments par rapport à la prise en charge de sa santé (par exemple, prendre la bonne dose de médicaments au bon moment, se rendre à ses rendez-vous chez le médecin), si votre

[redacted]



enfant sent que les infirmières et médecins soutiennent son autonome, et à quel point il/elle est satisfait (e) et heureux de sa vie.

Nous demanderons à votre enfant de nous retourner les questionnaires par la poste, dans une enveloppe prépayée. Également, les médecins pourraient regarder le dossier médical de votre enfant pour avoir plus d'informations.

Avantages et risques

Nous espérons que cette étude aidera à mieux comprendre les besoins des adolescents comme le vôtre et nous aidera à leur offrir de meilleurs traitements dans le futur.

Il n'y a pas de risque significatif. Si votre enfant se sent mal après avoir rempli le questionnaire, votre enfant peut communiquer avec la chercheuse principale qui l'aidera à obtenir du soutien.

Votre enfant recevra une lettre l'informant des résultats de l'étude.

Participation volontaire

La participation de votre enfant est volontaire et il n'est pas dans l'obligation de prendre part à l'étude. Même si votre enfant décide de participer maintenant, il/elle est libre de retirer son consentement en tout temps sans affecter la qualité des soins qu'il/elle reçoit. Si vous ou votre enfant décide de mettre fin à se participation, nous vous demandons d'en aviser la chercheuse principale, Tziona Lugasi. Vous ou votre enfant pouvez la rejoindre au [redacted]

Confidentialité

Toutes les informations obtenues durant l'étude sont confidentielles. Elles seront gardées sous clé au laboratoire de la chercheuse principale et elles seront conservées durant cinq ans après la fin de l'étude. Par la suite, les questionnaires seront détruits. Les résultats peuvent être annoncés dans des revues médicales, mais le nom de votre enfant ne sera jamais divulgué.

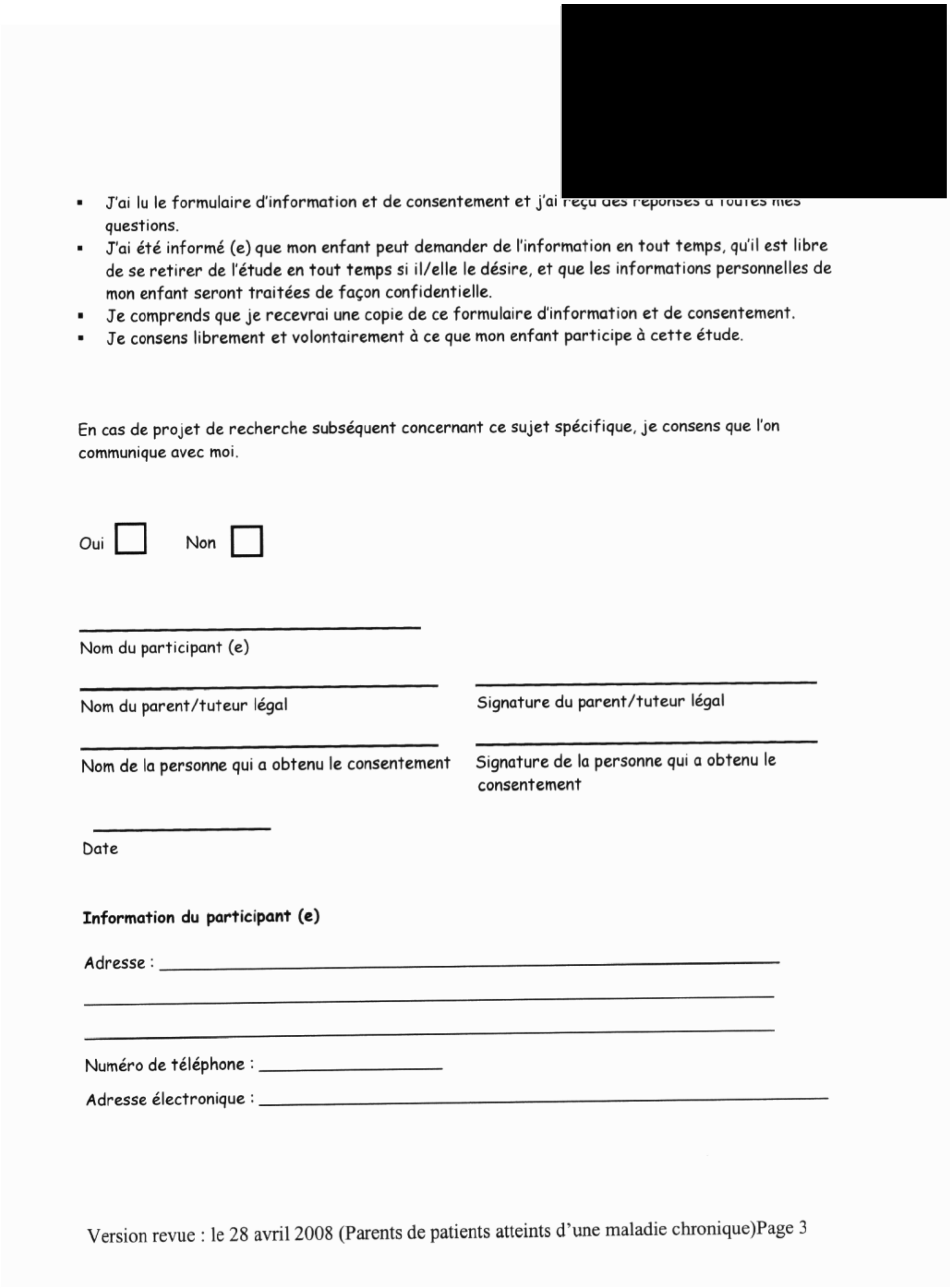
Les membres du bureau d'éthique de la recherche du CUSM ou des vérificateurs de Santé Canada auront le droit d'inspecter les données de l'étude pour des raisons d'assurance de la qualité.

Personnes disponibles pour répondre à vos questions

Si vous ou votre enfant avez des questions, vous pouvez rejoindre la chercheuse principale, Tziona Lugasi, par téléphone au [redacted]

Pour plus d'information à propos des droits de votre enfant en tant que participant à une étude, vous pouvez communiquer avec la représentante des patients au [redacted]

Consentement



- J'ai lu le formulaire d'information et de consentement et j'ai [redacted] questions.
- J'ai été informé (e) que mon enfant peut demander de l'information en tout temps, qu'il est libre de se retirer de l'étude en tout temps si il/elle le désire, et que les informations personnelles de mon enfant seront traitées de façon confidentielle.
- Je comprends que je recevrai une copie de ce formulaire d'information et de consentement.
- Je consens librement et volontairement à ce que mon enfant participe à cette étude.

En cas de projet de recherche subséquent concernant ce sujet spécifique, je consens que l'on communique avec moi.

Oui ☐ Non ☐

____
Nom du participant (e)

______________________________ Nom du parent/tuteur légal	______________________________ Signature du parent/tuteur légal
______________________________ Nom de la personne qui a obtenu le consentement	______________________________ Signature de la personne qui a obtenu le consentement

____
Date

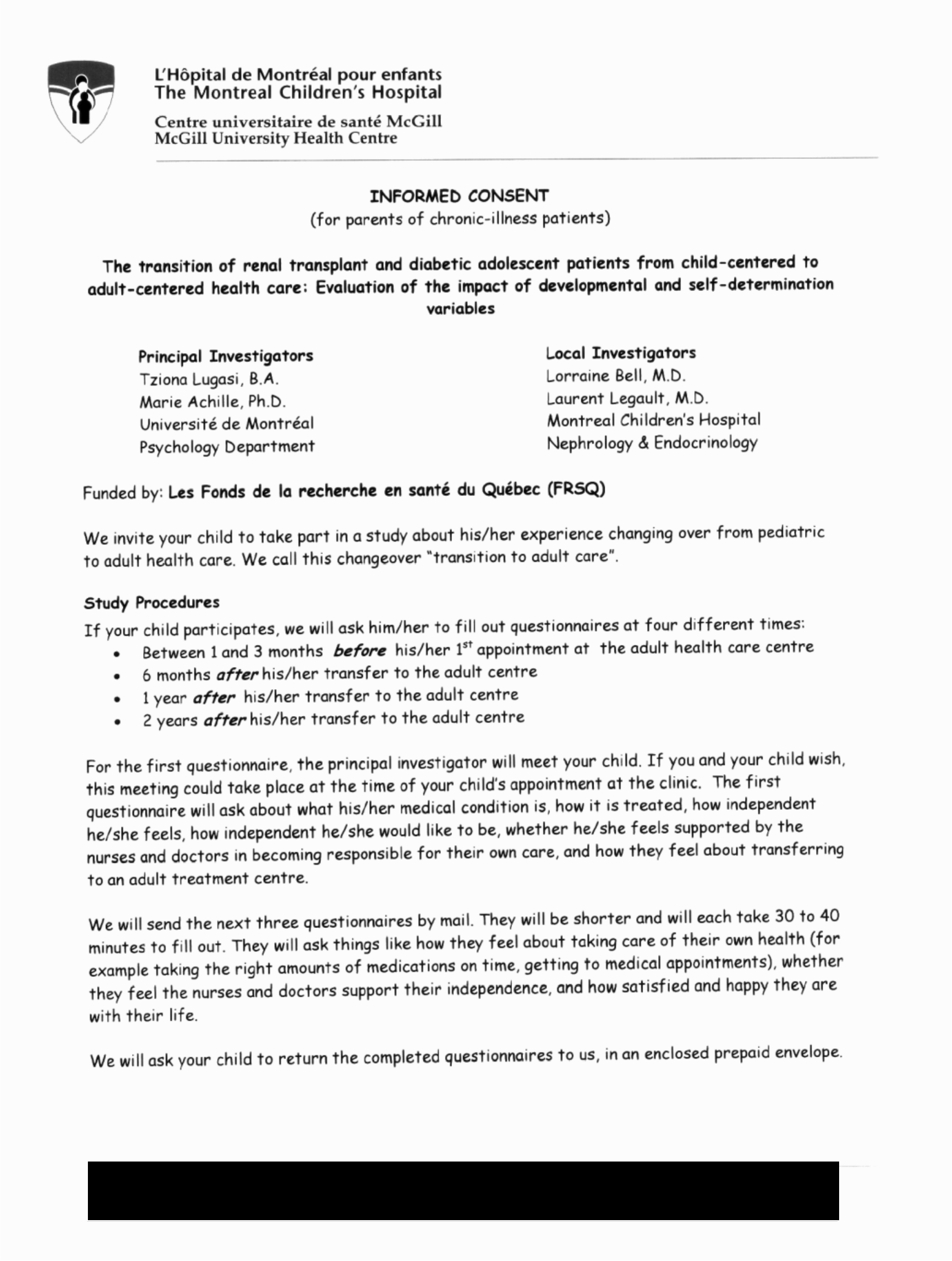
Information du participant (e)

Adresse : ____
____
____

Numéro de téléphone : _______________

Adresse électronique : ____

Version revue : le 28 avril 2008 (Parents de patients atteints d'une maladie chronique)Page 3



L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

INFORMED CONSENT

(for parents of chronic-illness patients)

The transition of renal transplant and diabetic adolescent patients from child-centered to adult-centered health care: Evaluation of the impact of developmental and self-determination variables

Principal Investigators	**Local Investigators**
Tziona Lugasi, B.A.	Lorraine Bell, M.D.
Marie Achille, Ph.D.	Laurent Legault, M.D.
Université de Montréal	Montreal Children's Hospital
Psychology Department	Nephrology & Endocrinology

Funded by: **Les Fonds de la recherche en santé du Québec (FRSQ)**

We invite your child to take part in a study about his/her experience changing over from pediatric to adult health care. We call this changeover "transition to adult care".

Study Procedures

If your child participates, we will ask him/her to fill out questionnaires at four different times:

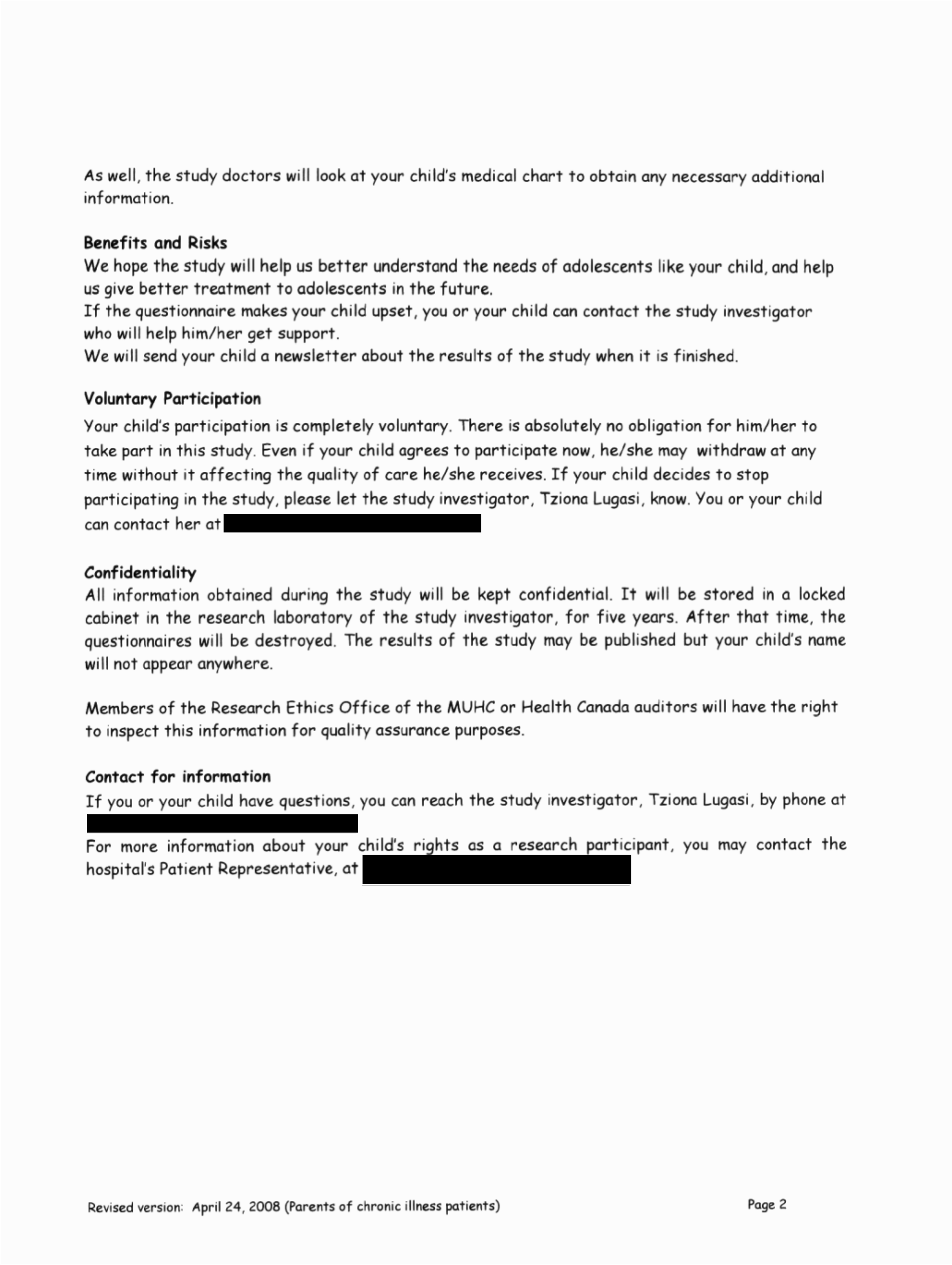
- Between 1 and 3 months ***before*** his/her 1st appointment at the adult health care centre
- 6 months ***after*** his/her transfer to the adult centre
- 1 year ***after*** his/her transfer to the adult centre
- 2 years ***after*** his/her transfer to the adult centre

For the first questionnaire, the principal investigator will meet your child. If you and your child wish, this meeting could take place at the time of your child's appointment at the clinic. The first questionnaire will ask about what his/her medical condition is, how it is treated, how independent he/she feels, how independent he/she would like to be, whether he/she feels supported by the nurses and doctors in becoming responsible for their own care, and how they feel about transferring to an adult treatment centre.

We will send the next three questionnaires by mail. They will be shorter and will each take 30 to 40 minutes to fill out. They will ask things like how they feel about taking care of their own health (for example taking the right amounts of medications on time, getting to medical appointments), whether they feel the nurses and doctors support their independence, and how satisfied and happy they are with their life.

We will ask your child to return the completed questionnaires to us, in an enclosed prepaid envelope.

[redacted]



As well, the study doctors will look at your child's medical chart to obtain any necessary additional information.

Benefits and Risks

We hope the study will help us better understand the needs of adolescents like your child, and help us give better treatment to adolescents in the future.

If the questionnaire makes your child upset, you or your child can contact the study investigator who will help him/her get support.

We will send your child a newsletter about the results of the study when it is finished.

Voluntary Participation

Your child's participation is completely voluntary. There is absolutely no obligation for him/her to take part in this study. Even if your child agrees to participate now, he/she may withdraw at any time without it affecting the quality of care he/she receives. If your child decides to stop participating in the study, please let the study investigator, Tziona Lugasi, know. You or your child can contact her at [redacted]

Confidentiality

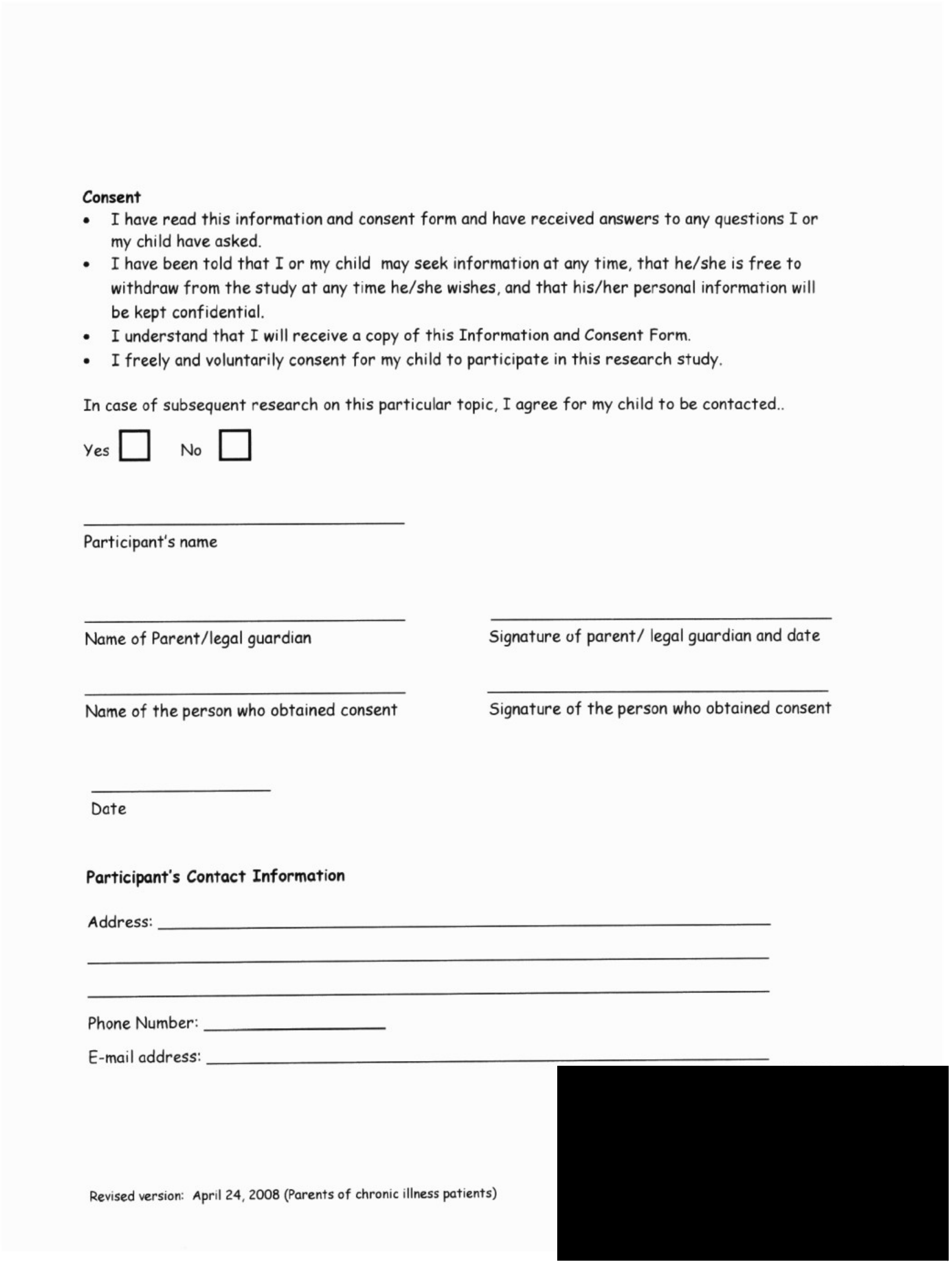
All information obtained during the study will be kept confidential. It will be stored in a locked cabinet in the research laboratory of the study investigator, for five years. After that time, the questionnaires will be destroyed. The results of the study may be published but your child's name will not appear anywhere.

Members of the Research Ethics Office of the MUHC or Health Canada auditors will have the right to inspect this information for quality assurance purposes.

Contact for information

If you or your child have questions, you can reach the study investigator, Tziona Lugasi, by phone at [redacted]

For more information about your child's rights as a research participant, you may contact the hospital's Patient Representative, at [redacted]



Consent

- I have read this information and consent form and have received answers to any questions I or my child have asked.
- I have been told that I or my child may seek information at any time, that he/she is free to withdraw from the study at any time he/she wishes, and that his/her personal information will be kept confidential.
- I understand that I will receive a copy of this Information and Consent Form.
- I freely and voluntarily consent for my child to participate in this research study.

In case of subsequent research on this particular topic, I agree for my child to be contacted..

Yes ☐ No ☐

____

Participant's name

____________________________ Name of Parent/legal guardian	____________________________ Signature of parent/ legal guardian and date
____________________________ Name of the person who obtained consent	____________________________ Signature of the person who obtained consent

____

Date

Participant's Contact Information

Address: ____

____

____

Phone Number: ________________

E-mail address: ____

Revised version: April 24, 2008 (Parents of chronic illness patients)

[redacted]

ANNEXE G

Formulaire de consentement du Manitoba Institute of Child Health

Children's Hospital
Health Sciences Centre Winnipeg
Pediatric Nephrology

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: **"The transition of renal transplant and diabetic adolescent patients from child-centered to adult-centered health care: Evaluation of the impact of developmental and self-determination variables".**

Principal Investigator: Dr. Tom Blydt-Hansen MD
[redacted]

Co-Investigator: Tziona Lugasi/ Marie Achille, Ph.D.
[redacted]

Sponsor: Les Fonds de la recherche en santé du Québec (FRSQ)
Astellas Pharma

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

We invite you to participate to a study that will last two years and that will concern your transition experience from pediatric health care to adult health care. This period can be difficult for the patient and his/her family because it involves many changes. The goal of this study is to evaluate specific factors that may play a role in the transition from pediatric to adult health care. More precisely, we wish to understand the impact of your psychological and social behaviour, as well as your feelings about autonomy and competence on your transition experience. As well, we wish to understand your quality of life (i.e. satisfaction) and your adherence to treatment following the transition.

A total of 91 participants will participate in this study

Study procedures

For this study, a total of two groups will be involved. The first group will include adolescent patients between the ages of 17 and 21 who have been diagnosed with Type 1 diabetes or have received a renal transplant and who have a set date of transfer to adult-health. The second group will include healthy adolescents who will be recruited in schools. Two groups are included in the study because we are interested in understanding if differences exist in the psychological and social development and quality of life of healthy adolescents and adolescents who have been diagnosed with Type 1 diabetes and renal failure.

If you decide to participate in this study, your participation will involve filling out a questionnaire at four different times. The first meeting will take place one to three months before your transition from pediatric to adult health care. This meeting could be the same day as your visit at the clinic. During this first meeting, a research assistant will meet you and will give you a questionnaire to fill out. This questionnaire will be about your psychological and social development, your feelings of autonomy and competence, as well as your quality of life (i.e. your satisfaction) and adherence to medical recommendations. The questionnaire should take 60 to 90 minutes to fill out. Also, doctors will have access to your medical chart in order to obtain additional information. The second questionnaire will be about your feelings of autonomy, competence, quality of life, and your treatment. It will be sent to you six months following your transition to adult health care. This questionnaire should take 30 to 40 minutes to fill out. The same questionnaire will be sent to you one year and two years following your transition to adult health care. Once you complete it, you can send it back to us at our costs. A compensation of $10 will be given to you upon completion and return of each questionnaire.

The researcher may decide to take you off this study if funding for the study stop.

You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first.

At the end of the study, you will receive a newsletter informing you of the results. Results will be treated collectively for all the participants who took part in the study; therefore you will not receive your individual results.
We do not see any risks or disadvantages associated to the participation in this study,

[redacted]

except for the time it takes to complete the questionnaires. However, you will be informed of any new information that may affect whether you want to continue taking part in this study.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit other people with Type 1 diabetes and renal failure in the future.

Costs

All the procedures, which will be performed as part of this study, are provided at no cost to you.

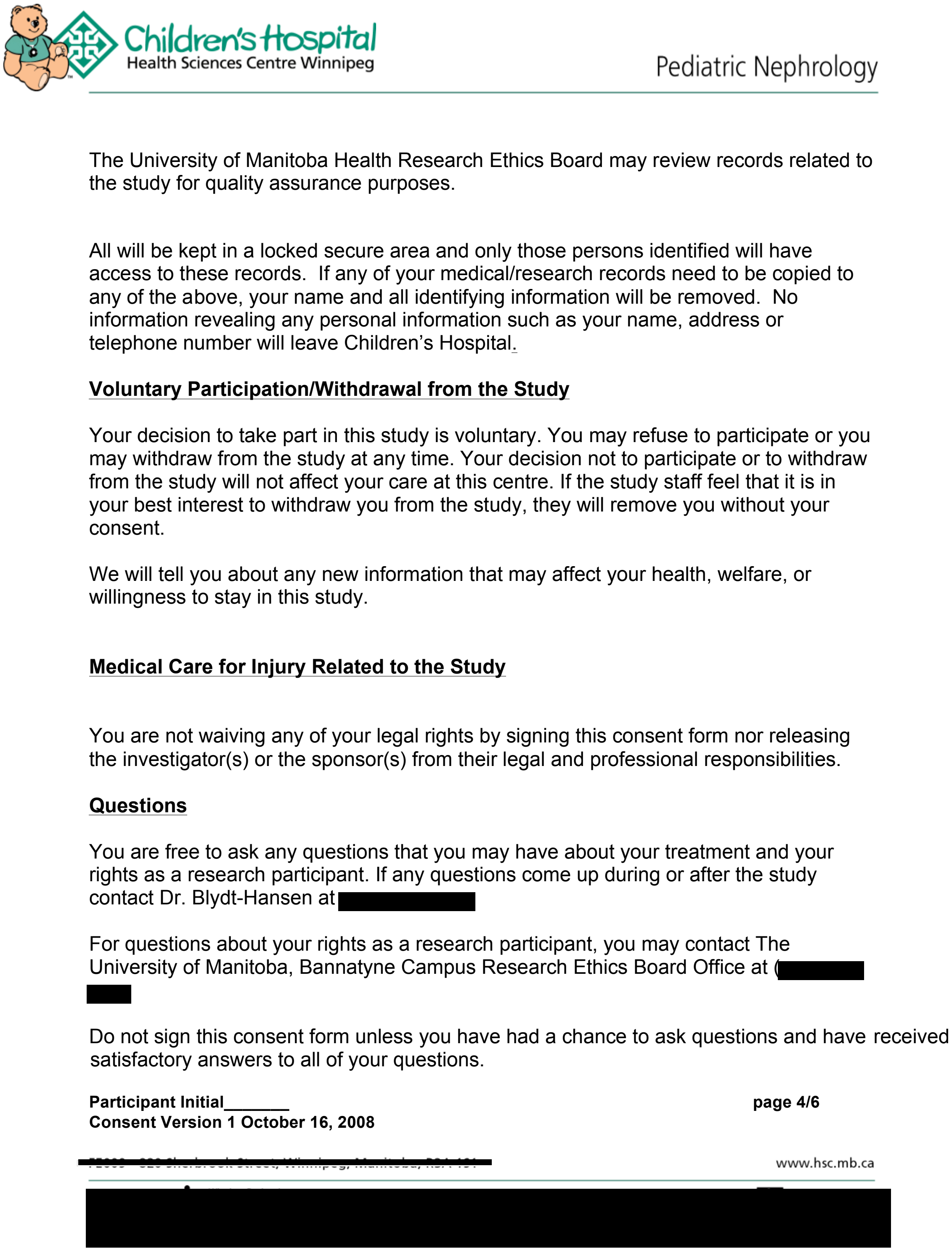
Payment for participation

You will be given $10 per completed questionnaire to a maximum of $40 upon termination of your participation in this research study. The investigator of the study will send you the amount of $10 by mail upon receipt of your completed questionnaire.

.

Confidentiality

Your medical and research records will be treated as confidential in accordance with the Personal Health Information Act of Manitoba. You will be identified by a code, and personal information from your record will not be released without your written permission. Efforts will be made to keep your personal information private. However, we cannot guarantee complete confidentiality. Your personal information may be disclosed if required by law. You will not be identified in any publication about this study. Data from this study will be entered into a computerized database through a secured website. Only study staff with a password will be allowed to enter data. All study data are identified by code, not by your name. The University of Manitoba Health Research Ethics Board, or other health authorities may review your medical and research records for regulatory purposes.
You have the right to the confidentiality of your answers. Your answers will not be discussed with your parents.



The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All will be kept in a locked secure area and only those persons identified will have access to these records. If any of your medical/research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave Children's Hospital.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feel that it is in your best interest to withdraw you from the study, they will remove you without your consent.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Medical Care for Injury Related to the Study

You are not waiving any of your legal rights by signing this consent form nor releasing the investigator(s) or the sponsor(s) from their legal and professional responsibilities.

Questions

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study contact Dr. Blydt-Hansen at [redacted]

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at ([redacted]

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Dr. Blydt-Hansen and or his/her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board, the ethics committees at CHU Sainte-Justine, the Montreal Children's Hospital, Les fonds de recherche en santé du Québec (the funding agency) , and the Ministry of Health and Social Services for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as participant in a research study.

[redacted]

[redacted]

I agree to be contacted for future follow-up in relation to this study,

Yes ___ No _____

Participant signature__________________________ Date____________________
(day/month/year)

Participant printed name: _____________________________

For patients under the age of 18:

Parent/legal guardian's signature______________________ Date______________
(day/month/year)

Parent/legal guardian's printed name: ______________________

Child's signature _________________________ Date ____________________
(day/month/year)

Child's printed name: _____________________________

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

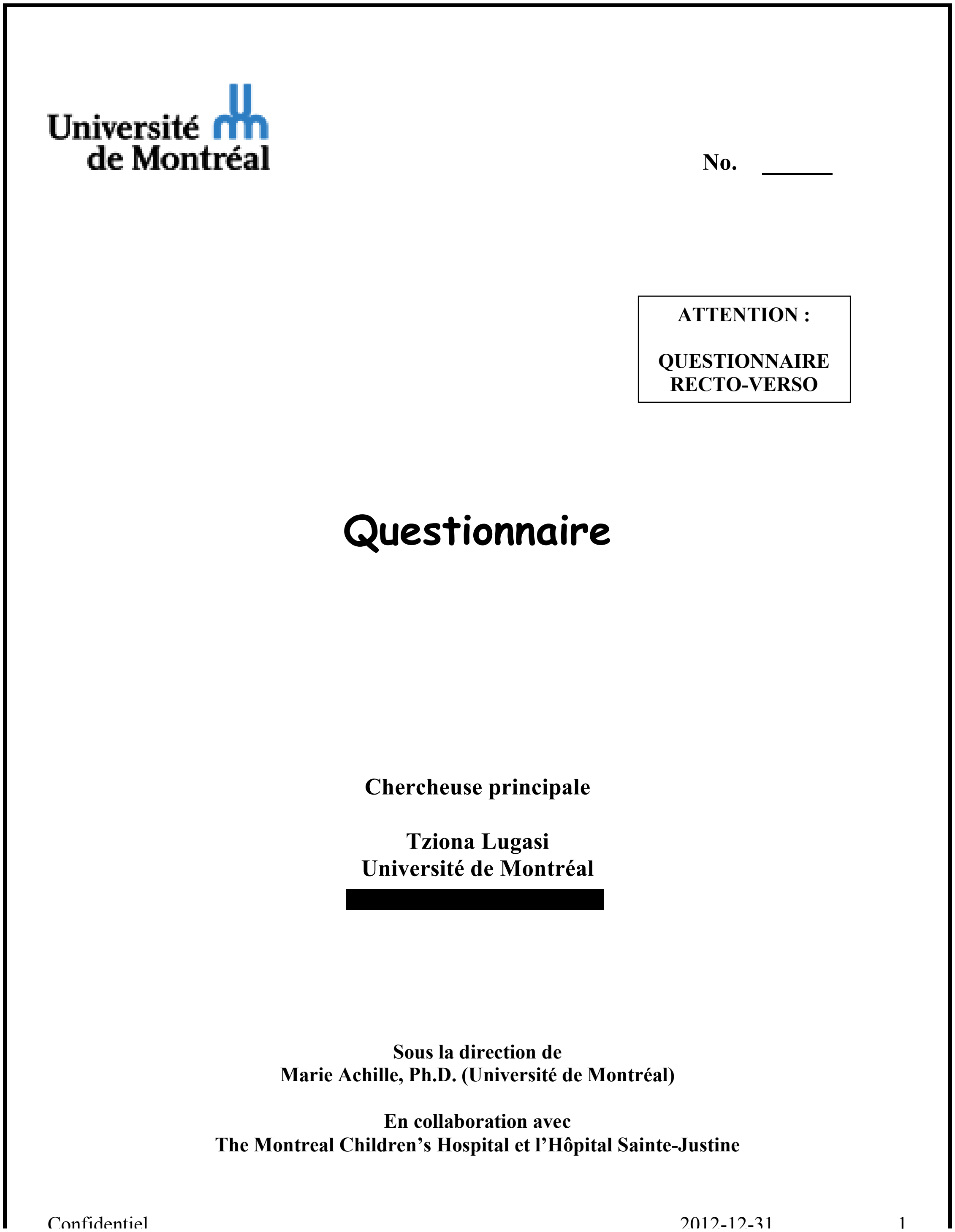
Printed Name: ____________________ Date____________________
(day/month/year)

Signature: _____________________________

"Role in the study: _____________________________

ANNEXE H

Questionnaire CEGEP



Université de Montréal

No. ______

ATTENTION :

QUESTIONNAIRE
RECTO-VERSO

Questionnaire

Chercheuse principale

Tziona Lugasi
Université de Montréal
[redacted]

Sous la direction de
Marie Achille, Ph.D. (Université de Montréal)

En collaboration avec
The Montreal Children's Hospital et l'Hôpital Sainte-Justine

Confidentiel 2012-12-31 1

Cher étudiant, chère étudiante,

Tout d'abord, je souhaite te remercier de prendre le temps de participer à cette étude. Ton temps ainsi que ton énergie sont grandement appréciés et nous espérons que les renseignements recueillis tout au long de cette étude serviront à faciliter la transition vers un centre pour adulte des adolescents chroniquement malades.

Ce questionnaire contient des questions concernant ton comportement psychologique et social, tes sentiments de compétence, ainsi que ta qualité de vie.

La plupart des questions sont à choix multiples et nous te demandons d'encercler la réponse qui te décrit le mieux. Il n'existe pas de bonne ou de mauvaise réponse aux questions, nous nous intéressons uniquement à ton vécu.

Si tu as des questions, n'hésite pas à me les poser. Il me fera plaisir de t'aider. Tu peux me contacter au numéro ou à l'adresse courriel indiqués au bas de la page.

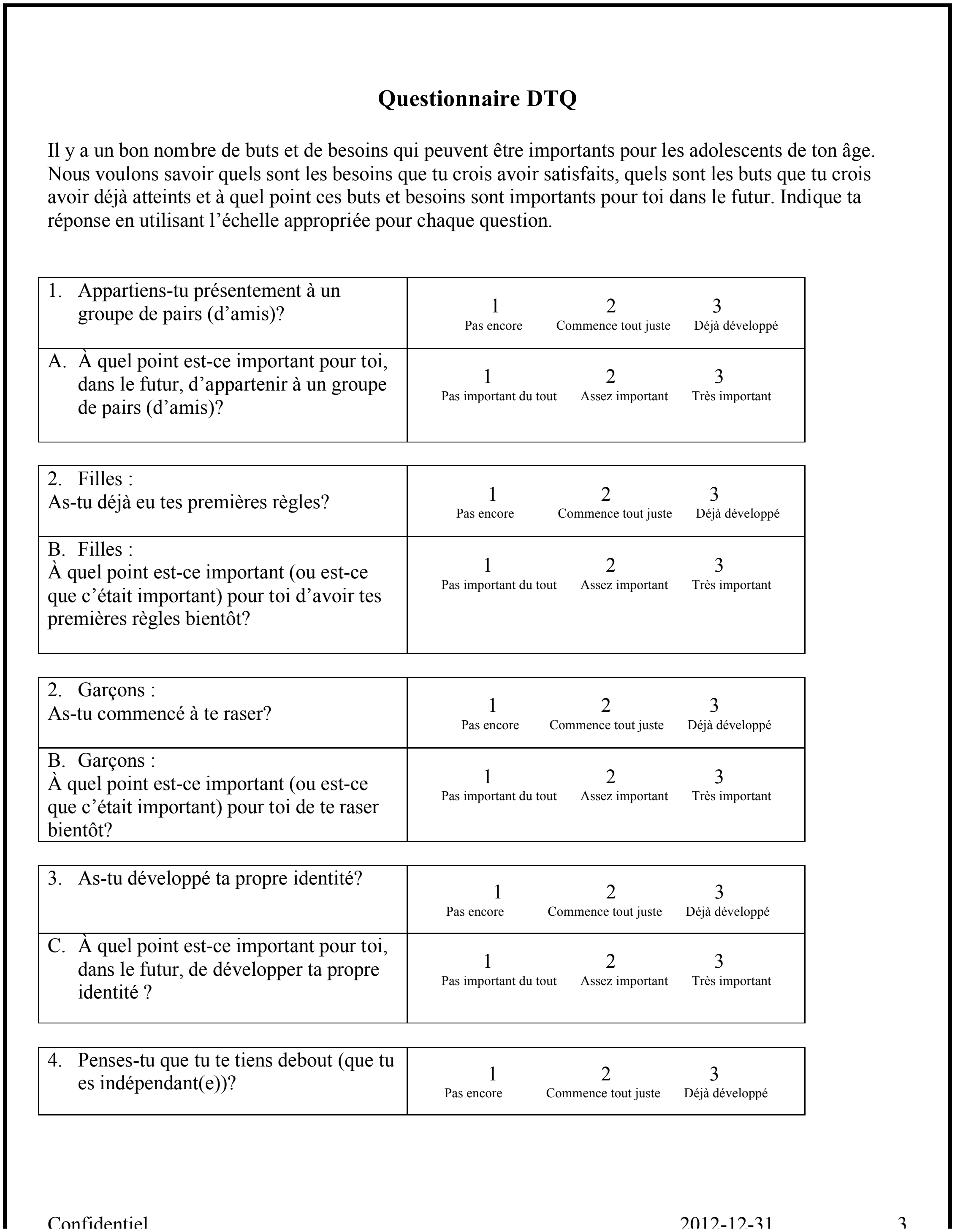
Je te remercie de ta participation!

Cordialement,

Tziona Lugasi

[redacted]

[redacted]



Questionnaire DTQ

Il y a un bon nombre de buts et de besoins qui peuvent être importants pour les adolescents de ton âge. Nous voulons savoir quels sont les besoins que tu crois avoir satisfaits, quels sont les buts que tu crois avoir déjà atteints et à quel point ces buts et besoins sont importants pour toi dans le futur. Indique ta réponse en utilisant l'échelle appropriée pour chaque question.

1. Appartiens-tu présentement à un groupe de pairs (d'amis)?	1 Pas encore 2 Commence tout juste 3 Déjà développé
A. À quel point est-ce important pour toi, dans le futur, d'appartenir à un groupe de pairs (d'amis)?	1 Pas important du tout 2 Assez important 3 Très important

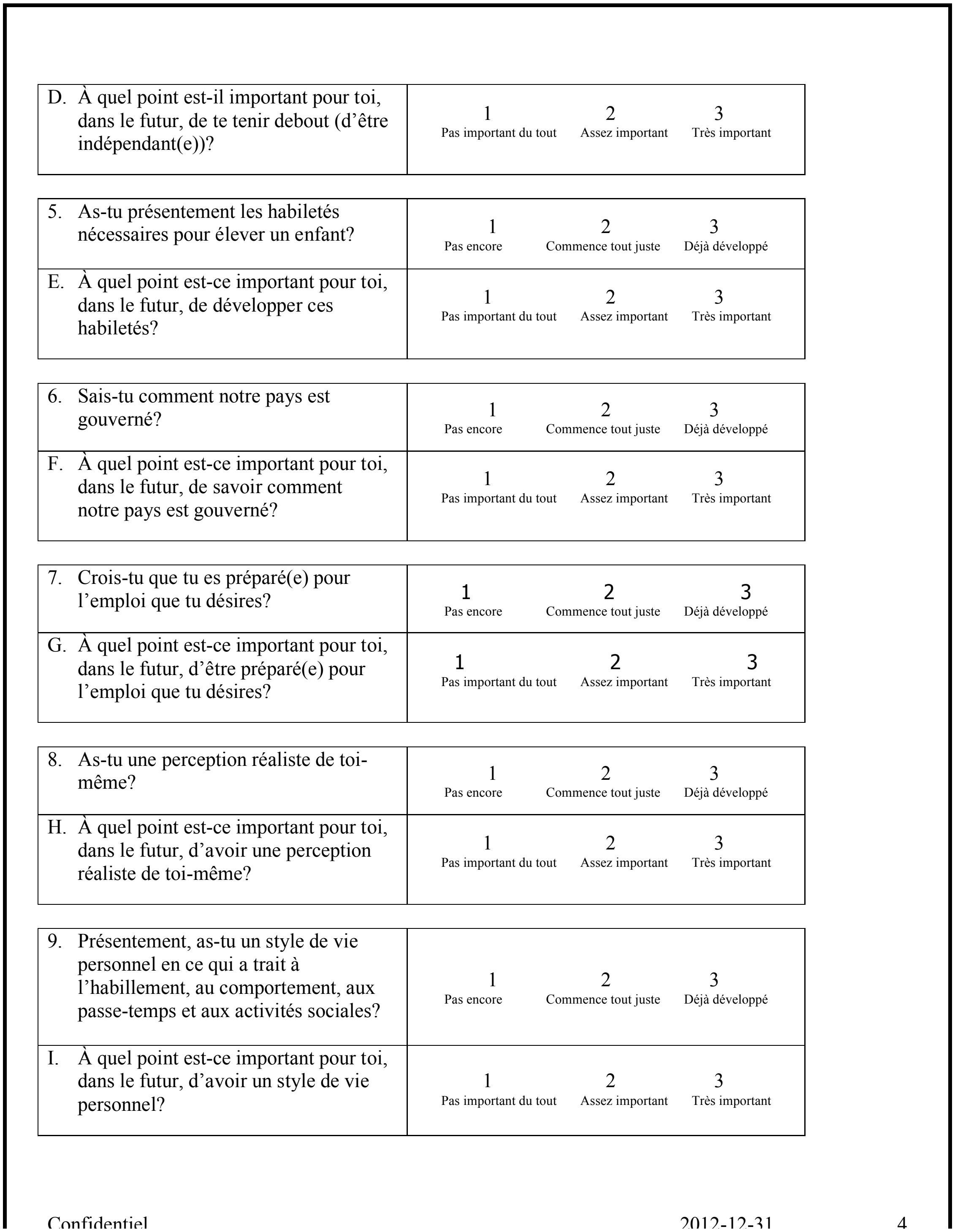
2. Filles : As-tu déjà eu tes premières règles?	1 Pas encore 2 Commence tout juste 3 Déjà développé
B. Filles : À quel point est-ce important (ou est-ce que c'était important) pour toi d'avoir tes premières règles bientôt?	1 Pas important du tout 2 Assez important 3 Très important

2. Garçons : As-tu commencé à te raser?	1 Pas encore 2 Commence tout juste 3 Déjà développé
B. Garçons : À quel point est-ce important (ou est-ce que c'était important) pour toi de te raser bientôt?	1 Pas important du tout 2 Assez important 3 Très important

3. As-tu développé ta propre identité?	1 Pas encore 2 Commence tout juste 3 Déjà développé
C. À quel point est-ce important pour toi, dans le futur, de développer ta propre identité ?	1 Pas important du tout 2 Assez important 3 Très important

4. Penses-tu que tu te tiens debout (que tu es indépendant(e))?	1 Pas encore 2 Commence tout juste 3 Déjà développé

Confidentiel 2012-12-31 3



D. À quel point est-il important pour toi, dans le futur, de te tenir debout (d'être indépendant(e))?	1 Pas important du tout	2 Assez important	3 Très important

5. As-tu présentement les habiletés nécessaires pour élever un enfant?	1 Pas encore	2 Commence tout juste	3 Déjà développé
E. À quel point est-ce important pour toi, dans le futur, de développer ces habiletés?	1 Pas important du tout	2 Assez important	3 Très important

6. Sais-tu comment notre pays est gouverné?	1 Pas encore	2 Commence tout juste	3 Déjà développé
F. À quel point est-ce important pour toi, dans le futur, de savoir comment notre pays est gouverné?	1 Pas important du tout	2 Assez important	3 Très important

7. Crois-tu que tu es préparé(e) pour l'emploi que tu désires?	1 Pas encore	2 Commence tout juste	3 Déjà développé
G. À quel point est-ce important pour toi, dans le futur, d'être préparé(e) pour l'emploi que tu désires?	1 Pas important du tout	2 Assez important	3 Très important

8. As-tu une perception réaliste de toi-même?	1 Pas encore	2 Commence tout juste	3 Déjà développé
H. À quel point est-ce important pour toi, dans le futur, d'avoir une perception réaliste de toi-même?	1 Pas important du tout	2 Assez important	3 Très important

9. Présentement, as-tu un style de vie personnel en ce qui a trait à l'habillement, au comportement, aux passe-temps et aux activités sociales?	1 Pas encore	2 Commence tout juste	3 Déjà développé
I. À quel point est-ce important pour toi, dans le futur, d'avoir un style de vie personnel?	1 Pas important du tout	2 Assez important	3 Très important

10. Es-tu présentement amoureux(se) d'un garçon / d'une fille?	1 Pas encore 2 Commence tout juste 3 Déjà développé
J. À quel point est-ce important pour toi, dans le futur, de tomber amoureux(se) d'un garçon / d'une fille?	1 Pas important du tout 2 Assez important 3 Très important

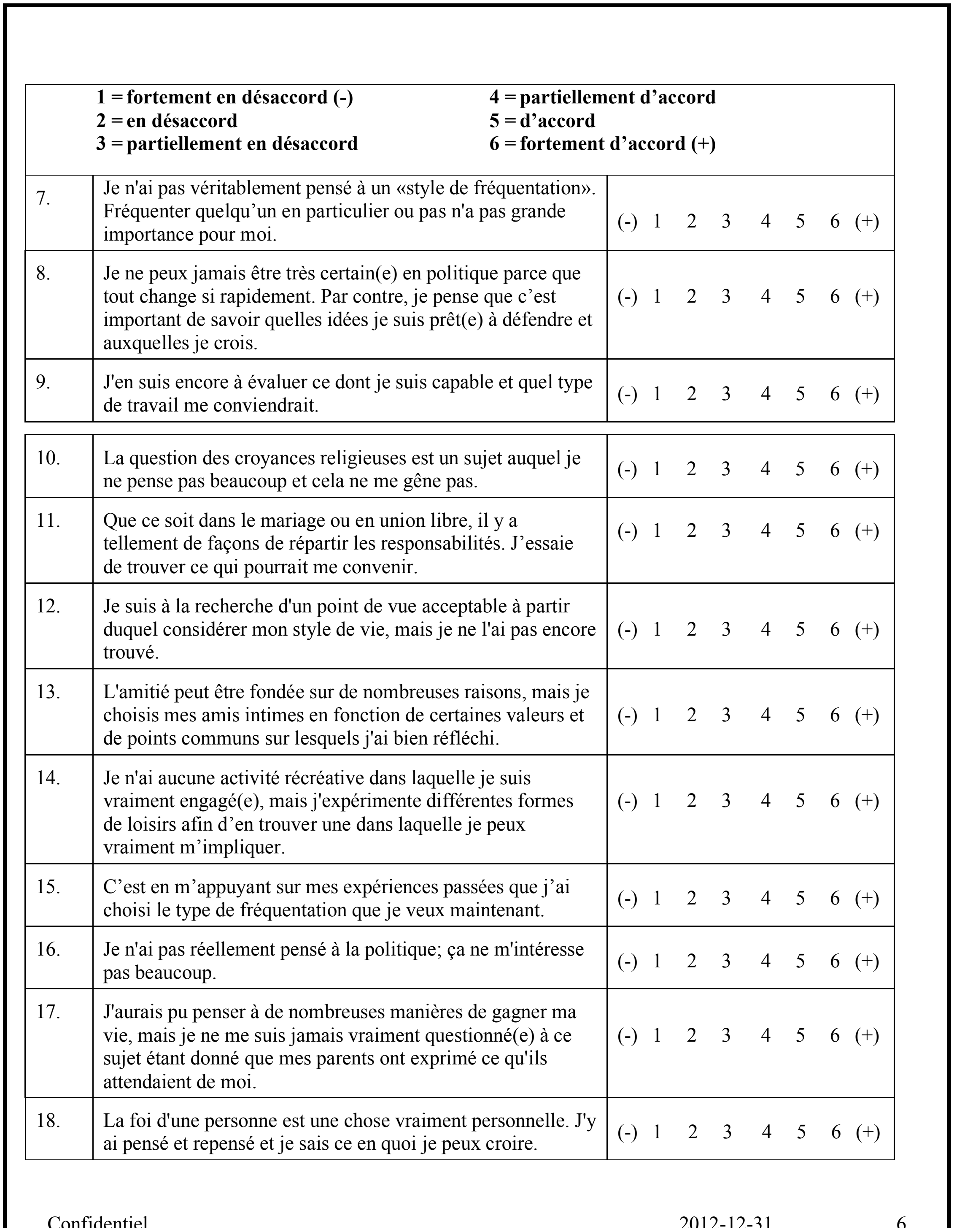
11. Fille : Présentement, as-tu une amie à qui tu peux parler de tout? Garçon : Présentement as-tu un ami à qui tu peux parler de tout	1 Pas encore 2 Commence tout juste 3 Déjà développé
K. À quel point est-ce important pour toi, dans le futur, d'avoir un tel ami / une telle amie?	1 Pas important du tout 2 Assez important 3 Très important

Questionnaire EOMEIS-2

Lis chaque question et encercle la réponse qui s'applique à toi.

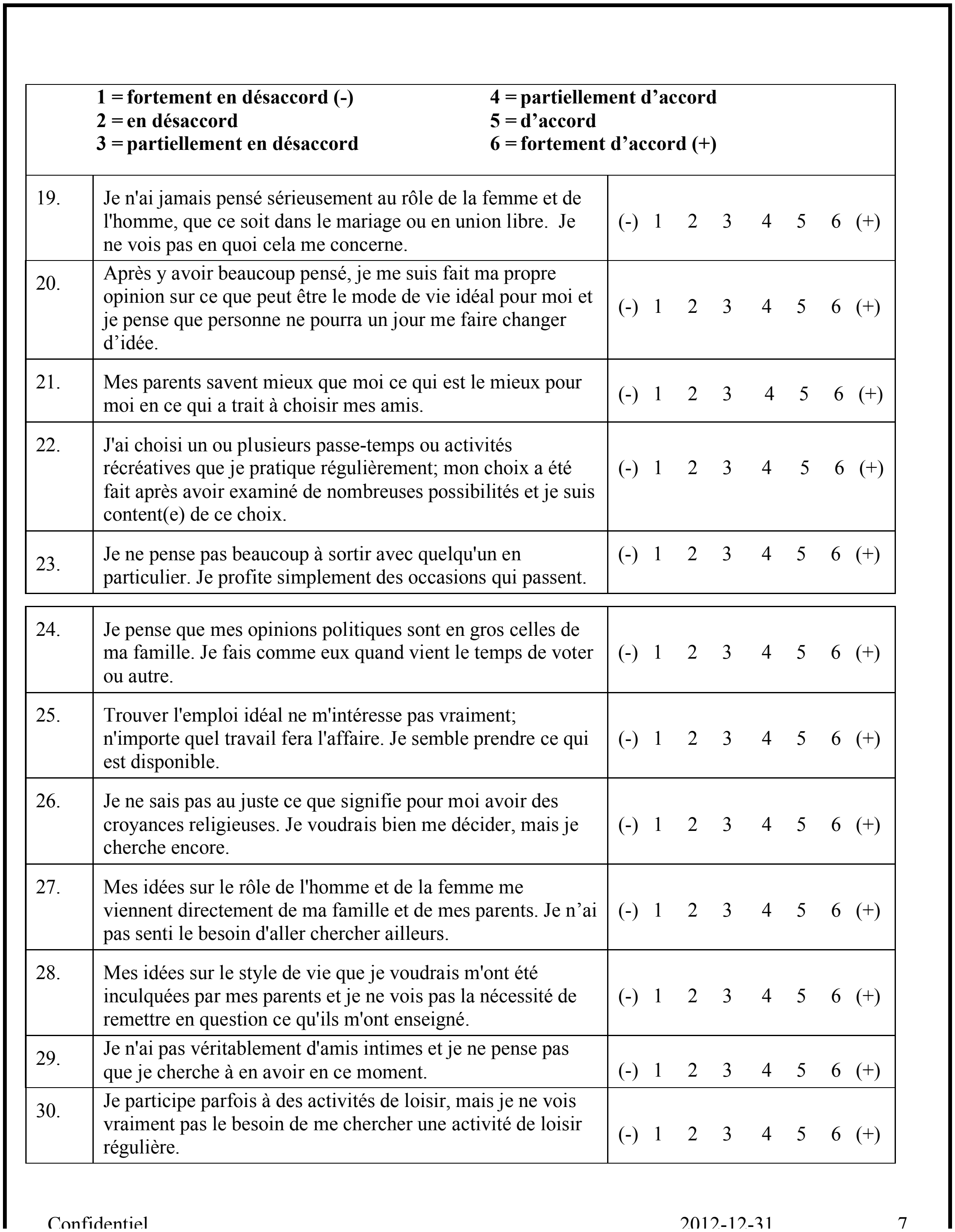
1 = fortement en désaccord (-)
2 = en désaccord
3 = partiellement en désaccord
4 = partiellement d'accord
5 = d'accord
6 = fortement d'accord (+)

1.	Je n'ai pas choisi l'emploi que je veux réellement occuper et je fais n'importe quel travail que je trouve en attendant mieux.	(-) 1 2 3 4 5 6 (+)
2.	En ce qui concerne les croyances religieuses, je n'ai simplement rien trouvé qui me tente et je ne ressens pas véritablement le besoin de chercher.	(-) 1 2 3 4 5 6 (+)
3.	Mes idées sur le rôle respectif de l'homme et de la femme sont les mêmes que celles de mes parents. Ce qui a bien marché pour eux marchera évidemment pour moi.	(-) 1 2 3 4 5 6 (+)
4.	Je n'ai pas de préférences pour un style de vie particulier plutôt qu'un autre.	(-) 1 2 3 4 5 6 (+)
5.	Il y a des gens de toutes sortes. J'en suis encore à explorer les nombreuses possibilités afin de trouver le bon type d'ami pour moi.	(-) 1 2 3 4 5 6 (+)
6.	Je m'implique parfois dans des passe-temps ou des activités récréatives lorsqu'on me le demande, mais j'essaie rarement quoi que ce soit par moi-même.	(-) 1 2 3 4 5 6 (+)



1 = fortement en désaccord (-)
2 = en désaccord
3 = partiellement en désaccord
4 = partiellement d’accord
5 = d’accord
6 = fortement d’accord (+)

7.	Je n'ai pas véritablement pensé à un «style de fréquentation». Fréquenter quelqu’un en particulier ou pas n'a pas grande importance pour moi.	(-) 1 2 3 4 5 6 (+)
8.	Je ne peux jamais être très certain(e) en politique parce que tout change si rapidement. Par contre, je pense que c’est important de savoir quelles idées je suis prêt(e) à défendre et auxquelles je crois.	(-) 1 2 3 4 5 6 (+)
9.	J'en suis encore à évaluer ce dont je suis capable et quel type de travail me conviendrait.	(-) 1 2 3 4 5 6 (+)
10.	La question des croyances religieuses est un sujet auquel je ne pense pas beaucoup et cela ne me gêne pas.	(-) 1 2 3 4 5 6 (+)
11.	Que ce soit dans le mariage ou en union libre, il y a tellement de façons de répartir les responsabilités. J’essaie de trouver ce qui pourrait me convenir.	(-) 1 2 3 4 5 6 (+)
12.	Je suis à la recherche d'un point de vue acceptable à partir duquel considérer mon style de vie, mais je ne l'ai pas encore trouvé.	(-) 1 2 3 4 5 6 (+)
13.	L'amitié peut être fondée sur de nombreuses raisons, mais je choisis mes amis intimes en fonction de certaines valeurs et de points communs sur lesquels j'ai bien réfléchi.	(-) 1 2 3 4 5 6 (+)
14.	Je n'ai aucune activité récréative dans laquelle je suis vraiment engagé(e), mais j'expérimente différentes formes de loisirs afin d’en trouver une dans laquelle je peux vraiment m’impliquer.	(-) 1 2 3 4 5 6 (+)
15.	C’est en m’appuyant sur mes expériences passées que j’ai choisi le type de fréquentation que je veux maintenant.	(-) 1 2 3 4 5 6 (+)
16.	Je n'ai pas réellement pensé à la politique; ça ne m'intéresse pas beaucoup.	(-) 1 2 3 4 5 6 (+)
17.	J'aurais pu penser à de nombreuses manières de gagner ma vie, mais je ne me suis jamais vraiment questionné(e) à ce sujet étant donné que mes parents ont exprimé ce qu'ils attendaient de moi.	(-) 1 2 3 4 5 6 (+)
18.	La foi d'une personne est une chose vraiment personnelle. J'y ai pensé et repensé et je sais ce en quoi je peux croire.	(-) 1 2 3 4 5 6 (+)



1 = fortement en désaccord (-)
2 = en désaccord
3 = partiellement en désaccord
4 = partiellement d'accord
5 = d'accord
6 = fortement d'accord (+)

19.	Je n'ai jamais pensé sérieusement au rôle de la femme et de l'homme, que ce soit dans le mariage ou en union libre. Je ne vois pas en quoi cela me concerne.	(-) 1 2 3 4 5 6 (+)
20.	Après y avoir beaucoup pensé, je me suis fait ma propre opinion sur ce que peut être le mode de vie idéal pour moi et je pense que personne ne pourra un jour me faire changer d'idée.	(-) 1 2 3 4 5 6 (+)
21.	Mes parents savent mieux que moi ce qui est le mieux pour moi en ce qui a trait à choisir mes amis.	(-) 1 2 3 4 5 6 (+)
22.	J'ai choisi un ou plusieurs passe-temps ou activités récréatives que je pratique régulièrement; mon choix a été fait après avoir examiné de nombreuses possibilités et je suis content(e) de ce choix.	(-) 1 2 3 4 5 6 (+)
23.	Je ne pense pas beaucoup à sortir avec quelqu'un en particulier. Je profite simplement des occasions qui passent.	(-) 1 2 3 4 5 6 (+)
24.	Je pense que mes opinions politiques sont en gros celles de ma famille. Je fais comme eux quand vient le temps de voter ou autre.	(-) 1 2 3 4 5 6 (+)
25.	Trouver l'emploi idéal ne m'intéresse pas vraiment; n'importe quel travail fera l'affaire. Je semble prendre ce qui est disponible.	(-) 1 2 3 4 5 6 (+)
26.	Je ne sais pas au juste ce que signifie pour moi avoir des croyances religieuses. Je voudrais bien me décider, mais je cherche encore.	(-) 1 2 3 4 5 6 (+)
27.	Mes idées sur le rôle de l'homme et de la femme me viennent directement de ma famille et de mes parents. Je n'ai pas senti le besoin d'aller chercher ailleurs.	(-) 1 2 3 4 5 6 (+)
28.	Mes idées sur le style de vie que je voudrais m'ont été inculquées par mes parents et je ne vois pas la nécessité de remettre en question ce qu'ils m'ont enseigné.	(-) 1 2 3 4 5 6 (+)
29.	Je n'ai pas véritablement d'amis intimes et je ne pense pas que je cherche à en avoir en ce moment.	(-) 1 2 3 4 5 6 (+)
30.	Je participe parfois à des activités de loisir, mais je ne vois vraiment pas le besoin de me chercher une activité de loisir régulière.	(-) 1 2 3 4 5 6 (+)

1 = fortement en désaccord (-) | **4 = partiellement d’accord**
2 = en désaccord | **5 = d’accord**
3 = partiellement en désaccord | **6 = fortement d’accord (+)**

31.	J’essaie présentement plusieurs manières de fréquenter (un garçon, une fille), mais je n’ai pas encore décidé quelle était la meilleure pour moi.	(-) 1 2 3 4 5 6 (+)
32.	Il y a tellement de partis et d'idéaux politiques. Je ne peux pas décider lesquels suivre jusqu’à ce que je sois arrivé(e) à y voir plus clair.	(-) 1 2 3 4 5 6 (+)
33.	J'ai eu du mal à décider, mais maintenant je sais vraiment quelle carrière je voudrais poursuivre.	(-) 1 2 3 4 5 6 (+)
34.	En ce moment, je suis confus(e) par rapport aux croyances religieuses. Je change continuellement d'idée sur ce qui est bon ou mauvais pour moi.	(-) 1 2 3 4 5 6 (+)
35.	Que ce soit dans le mariage ou en union libre, j'ai passé un certain temps à réfléchir sur le rôle de l'homme et de la femme et j'ai décidé ce qui serait meilleur pour moi.	(-) 1 2 3 4 5 6 (+)
36.	La recherche d'un point de vue acceptable sur la vie elle-même m'entraîne dans de nombreuses discussions avec les autres et me porte à réfléchir sur moi-même.	(-) 1 2 3 4 5 6 (+)
37.	Je ne me lie d'amitié qu'avec des gens qui auraient l'approbation de mes parents.	(-) 1 2 3 4 5 6 (+)
38.	J'ai toujours aimé les mêmes activités de loisir que mes parents et je n'ai jamais pensé sérieusement à en avoir d'autres.	(-) 1 2 3 4 5 6 (+)
39.	Quand il s’agit de fréquenter quelqu’un en particulier, je ne fréquente qu'une personne qui correspond au type de personne auquel mes parents s'attendent.	(-) 1 2 3 4 5 6 (+)
40.	J'ai bien réfléchi à mes convictions politiques et je réalise que je peux être d'accord avec certaines idées de mes parents sans être d'accord avec toutes leurs idées.	(-) 1 2 3 4 5 6 (+)
41.	Mes parents ont décidé depuis longtemps quel type de travail je devais faire et je suis le plan de carrière qu'ils m’ont tracé.	(-) 1 2 3 4 5 6 (+)
42.	Pendant un certain temps, je me suis interrogé(e) sérieusement sur la foi et je peux maintenant dire que je comprends ce en quoi je crois.	(-) 1 2 3 4 5 6 (+)

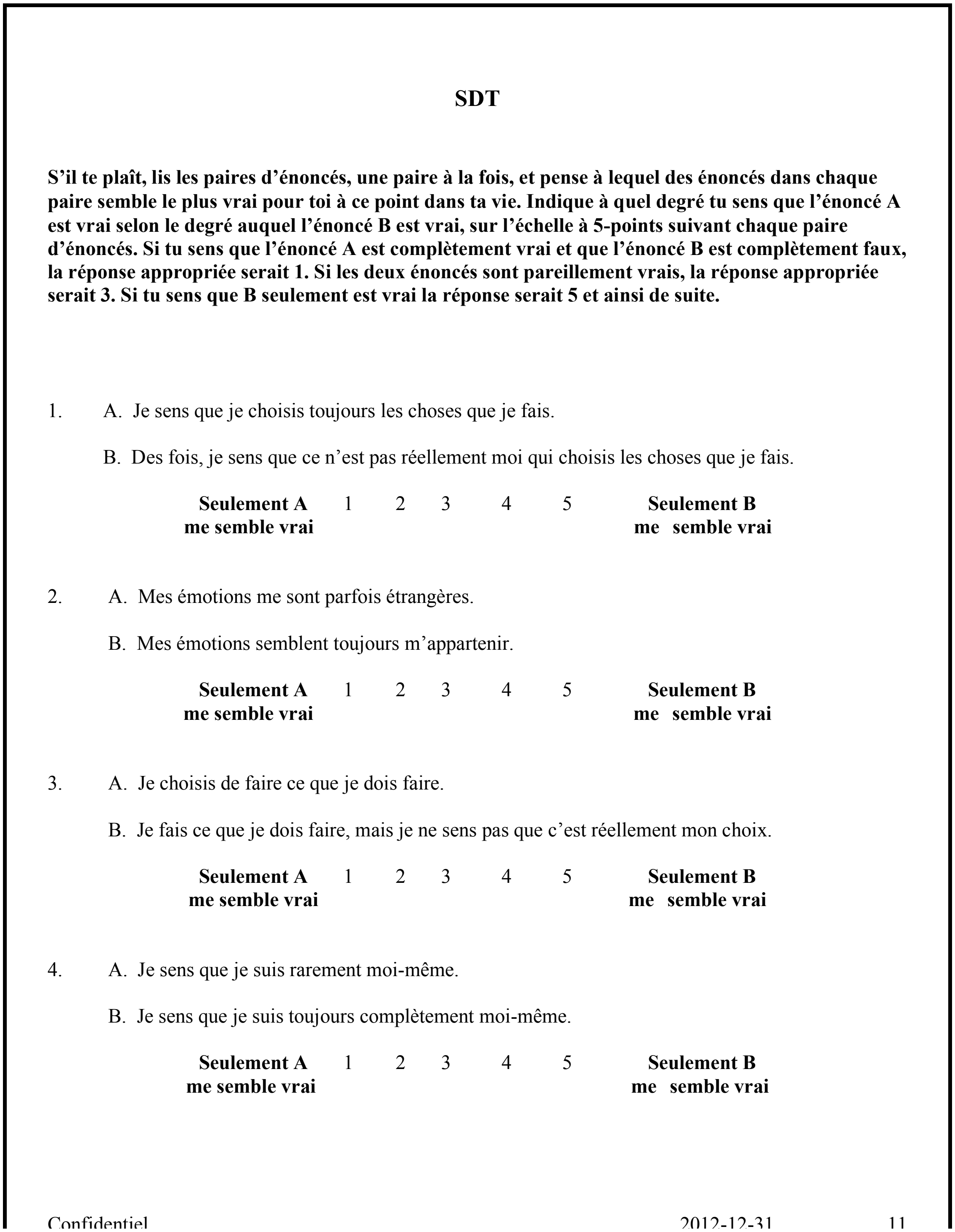
1 = fortement en désaccord (-)
2 = en désaccord
3 = partiellement en désaccord
4 = partiellement d'accord
5 = d'accord
6 = fortement d'accord (+)

43.	Que ce soit dans le mariage ou en union libre, j'ai beaucoup pensé ces derniers temps au rôle que jouent les hommes et les femmes et j'essaie de me faire une idée définitive.	(-) 1 2 3 4 5 6 (+)
44.	Les opinions des mes parents sur la vie me suffisent et je n'ai besoin de rien d'autre.	(-) 1 2 3 4 5 6 (+)
45.	J'ai essayé de nombreuses formes d'amitié et je sais maintenant ce que j'attends d'un ami.	(-) 1 2 3 4 5 6 (+)
46.	Après avoir essayé de nombreux hobbys et passe-temps, j'en ai trouvé un ou plusieurs que j'aime faire, seul(e) ou avec des ami(e)s.	(-) 1 2 3 4 5 6 (+)
47.	Je suis encore en train de développer mes préférences en ce qui concerne ma manière de fréquenter quelqu'un. Je ne suis pas encore complètement décidé(e).	(-) 1 2 3 4 5 6 (+)
48.	Je ne suis pas sûr(e) de mes convictions politiques, mais j'essaie de trouver ce en quoi je peux vraiment croire.	(-) 1 2 3 4 5 6 (+)
49.	J'ai mis longtemps à me décider, mais maintenant je suis certain(e) de la direction que je veux prendre pour ma carrière.	(-) 1 2 3 4 5 6 (+)
50.	J'ai les mêmes croyances que mes parents en ce qui concerne la religion. Je ne me suis jamais demandé(e) pourquoi.	(-) 1 2 3 4 5 6 (+)

51.	Que ce soit dans le mariage ou en union libre, les couples peuvent se répartir les responsabilités familiales de nombreuses façons. J'ai pensé à de nombreuses options et je sais maintenant exactement comment je voudrais que cela se passe pour moi.	(-) 1 2 3 4 5 6 (+)
52.	J'ai l'impression que je profite de la vie en général et je ne vois pas la nécessité pour moi d'adopter une philosophie de vie particulière.	(-) 1 2 3 4 5 6 (+)
53.	Je n'ai pas d'ami(e) intime. J'aime simplement me retrouver avec les copains / copines.	(-) 1 2 3 4 5 6 (+)
54.	J'expérimente plusieurs activités de loisir dans l'espoir d'en trouver au moins une qui pourrait me plaire pendant un certain temps.	(-) 1 2 3 4 5 6 (+)

1 = fortement en désaccord (-)
2 = en désaccord
3 = partiellement en désaccord
4 = partiellement d'accord
5 = d'accord
6 = fortement d'accord (+)

55.	J'ai fréquenté différents types de personnes et maintenant je sais exactement quelles sont mes propres « règles non écrites » pour les sorties et avec qui j'accepte de sortir.	(-) 1 2 3 4 5 6 (+)
56.	Je ne me suis jamais senti(e) suffisamment concerné(e) par la politique pour prendre position de manière ferme d'un côté ou de l'autre.	(-) 1 2 3 4 5 6 (+)
57.	Je n'arrive vraiment pas à décider de ce que je veux faire. Il y a tellement de choix de carrière.	(-) 1 2 3 4 5 6 (+)
58.	Je n'ai jamais vraiment mis en question mes croyances concernant la religion. Si elles sont bonnes pour mes parents, elles doivent être bonnes pour moi aussi.	(-) 1 2 3 4 5 6 (+)
59.	Les opinions par rapport aux hommes et aux femmes semblent si diversifiées que ça ne sert à rien pour moi de m'y attarder.	(-) 1 2 3 4 5 6 (+)
60.	Après m'être examiné(e) et interrogé(e) de manière approfondie, je me suis fait une opinion très nette de ce que devrait être mon style de vie.	(-) 1 2 3 4 5 6 (+)
61.	Je ne sais pas vraiment quel type d'ami serait le meilleur pour moi. J'essaie de trouver ce que veut vraiment dire l'amitié pour moi.	(-) 1 2 3 4 5 6 (+)
62.	Toutes mes préférences pour les activités de loisir me viennent de mes parents et je n'en ai pas vraiment essayé d'autres.	(-) 1 2 3 4 5 6 (+)
63.	Je ne fréquente que des personnes que mes parents approuveraient.	(-) 1 2 3 4 5 6 (+)
64.	Mes parents ont toujours eu leurs propres opinions politiques et morales sur des sujets tels que l'avortement et l'euthanasie et j'ai toujours accepté leur opinion.	(-) 1 2 3 4 5 6 (+)



SDT

S'il te plaît, lis les paires d'énoncés, une paire à la fois, et pense à lequel des énoncés dans chaque paire semble le plus vrai pour toi à ce point dans ta vie. Indique à quel degré tu sens que l'énoncé A est vrai selon le degré auquel l'énoncé B est vrai, sur l'échelle à 5-points suivant chaque paire d'énoncés. Si tu sens que l'énoncé A est complètement vrai et que l'énoncé B est complètement faux, la réponse appropriée serait 1. Si les deux énoncés sont pareillement vrais, la réponse appropriée serait 3. Si tu sens que B seulement est vrai la réponse serait 5 et ainsi de suite.

1. A. Je sens que je choisis toujours les choses que je fais.

   B. Des fois, je sens que ce n'est pas réellement moi qui choisis les choses que je fais.

   Seulement A me semble vrai 1 2 3 4 5 **Seulement B me semble vrai**

2. A. Mes émotions me sont parfois étrangères.

   B. Mes émotions semblent toujours m'appartenir.

   Seulement A me semble vrai 1 2 3 4 5 **Seulement B me semble vrai**

3. A. Je choisis de faire ce que je dois faire.

   B. Je fais ce que je dois faire, mais je ne sens pas que c'est réellement mon choix.

   Seulement A me semble vrai 1 2 3 4 5 **Seulement B me semble vrai**

4. A. Je sens que je suis rarement moi-même.

   B. Je sens que je suis toujours complètement moi-même.

   Seulement A me semble vrai 1 2 3 4 5 **Seulement B me semble vrai**

5. A. Je fais ce que je fais parce que ça m’intéresse.

B. Je fais ce que je fais parce que je dois le faire.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

6. A. Quand j’accomplis quelque chose, je sens souvent que ce n’est pas vraiment moi qui l’ai fait.

B. Quand j’accomplis quelque chose, je sens toujours que c’est moi qui l’ai fait.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

7. A. Je suis libre de faire tout ce que je décide de faire.

B. Ce que je fais n’est souvent pas ce que je choisirais de faire.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

8. A. Je sens parfois que mon corps m’est étranger.

B. Je sens toujours que mon corps fait partie de moi.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

9. A. Je me sens assez libre de faire tout ce que je choisis.

B. Je fais souvent des choses que je ne choisis pas de faire.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

10. A. Parfois je regarde dans le miroir et je vois un étranger.

B. Quand je regarde dans le miroir c’est moi-même que je vois.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

Profil de qualité de vie : adolescents

Ce questionnaire comprend 54 items, soit 6 items pour 9 domaines de la vie. Chacune des questions doit être est cotée selon :

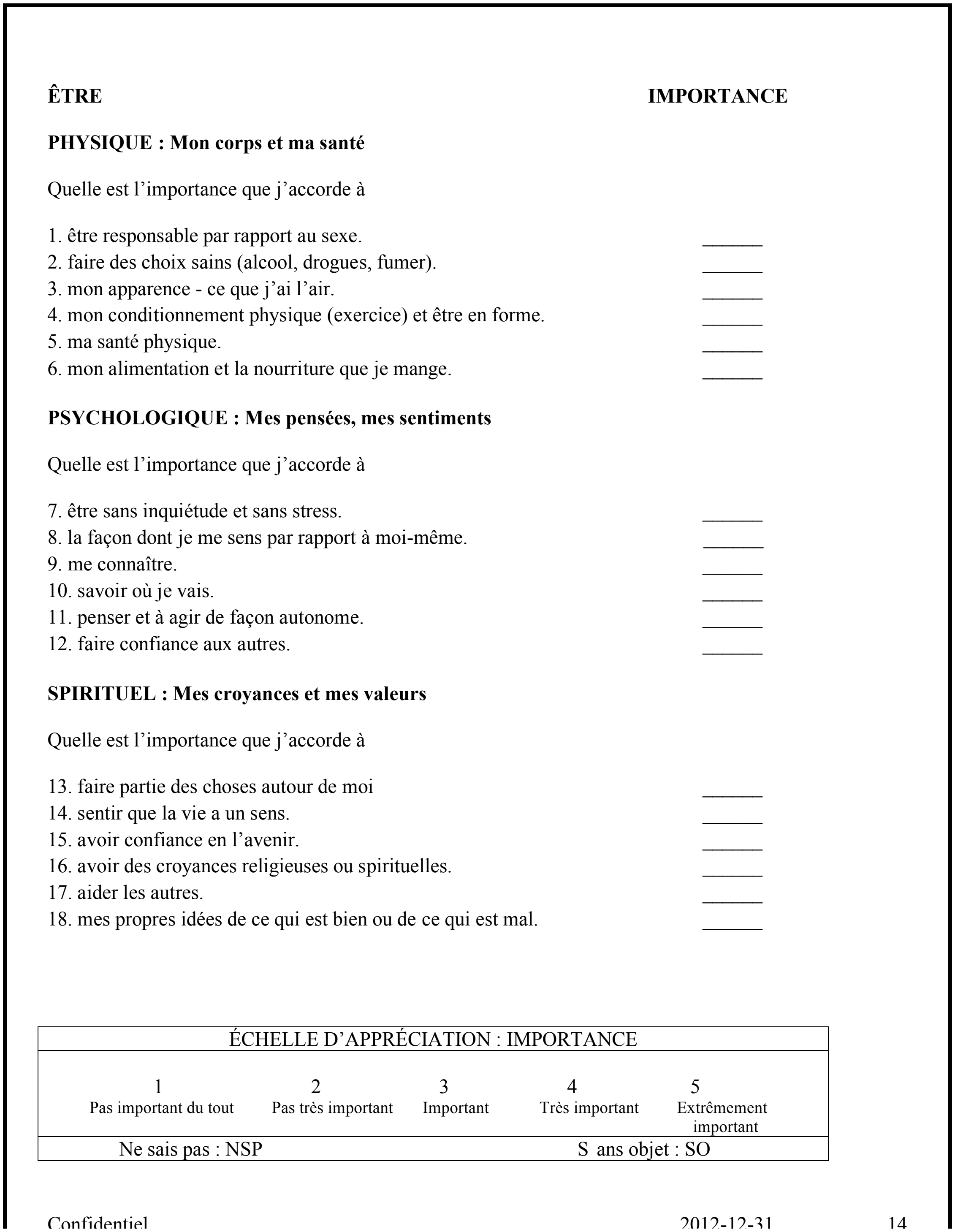
- son importance pour toi
- ton niveau de satisfaction par rapport au contenu de la question

De plus, les neuf domaines de vie sont cotés selon :

- le degré de contrôle que tu as dans ce domaine
- s'il y a des occasions d'amélioration ou de changement

Lorsque tu cotes chacune des sections :

- Donne une note de 1 à 5 à chaque question, en utilisant l'échelle d'appréciation au bas de chaque page.
- Réponds à chaque question concernant ta vie, telle que tu la vis présentement.
- Réponds à chaque question, même si tu ne peux pas présentement participer aux activités décrites. Par exemple, avoir un emploi peut être important pour toi, même si tu n'en as pas un. De la même façon, tu pourrais ne pas être insatisfait(e) du fait que tu n'as pas d'emploi.
- Si tu sens que la question ne s'applique pas à toi, donne une cote SO (Sans Objet).
- Si tu ne peux pas répondre à la question parce que tu n'es pas certain(e), donne-lui une cote NSP (Ne Sais Pas).
- Réponds franchement et de ton mieux aux questions.



ÊTRE **IMPORTANCE**

PHYSIQUE : Mon corps et ma santé

Quelle est l'importance que j'accorde à

1. être responsable par rapport au sexe. ______
2. faire des choix sains (alcool, drogues, fumer). ______
3. mon apparence - ce que j'ai l'air. ______
4. mon conditionnement physique (exercice) et être en forme. ______
5. ma santé physique. ______
6. mon alimentation et la nourriture que je mange. ______

PSYCHOLOGIQUE : Mes pensées, mes sentiments

Quelle est l'importance que j'accorde à

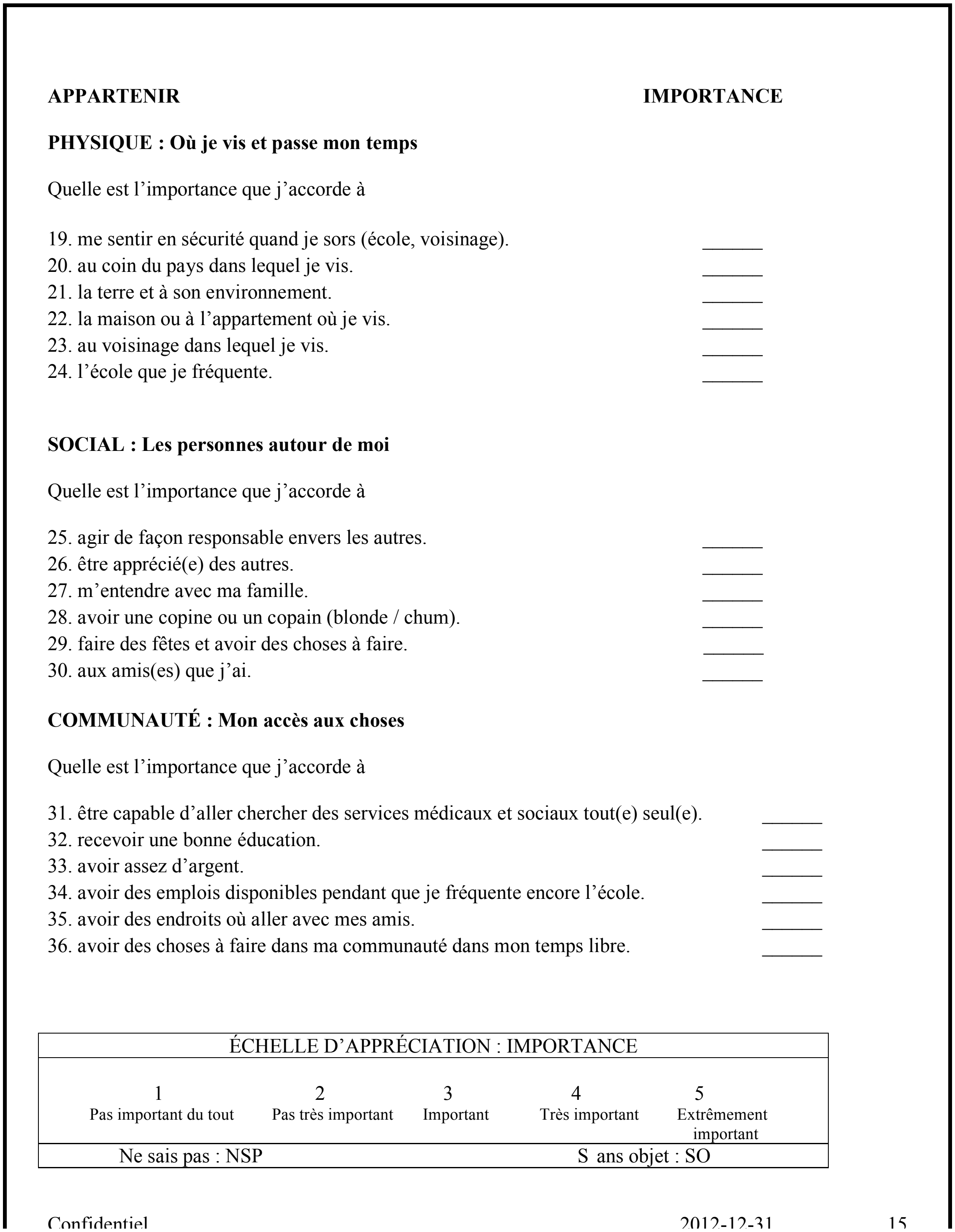
7. être sans inquiétude et sans stress. ______
8. la façon dont je me sens par rapport à moi-même. ______
9. me connaître. ______
10. savoir où je vais. ______
11. penser et à agir de façon autonome. ______
12. faire confiance aux autres. ______

SPIRITUEL : Mes croyances et mes valeurs

Quelle est l'importance que j'accorde à

13. faire partie des choses autour de moi ______
14. sentir que la vie a un sens. ______
15. avoir confiance en l'avenir. ______
16. avoir des croyances religieuses ou spirituelles. ______
17. aider les autres. ______
18. mes propres idées de ce qui est bien ou de ce qui est mal. ______

ÉCHELLE D'APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			S ans objet : SO	



APPARTENIR **IMPORTANCE**

PHYSIQUE : Où je vis et passe mon temps

Quelle est l'importance que j'accorde à

19. me sentir en sécurité quand je sors (école, voisinage). ______
20. au coin du pays dans lequel je vis. ______
21. la terre et à son environnement. ______
22. la maison ou à l'appartement où je vis. ______
23. au voisinage dans lequel je vis. ______
24. l'école que je fréquente. ______

SOCIAL : Les personnes autour de moi

Quelle est l'importance que j'accorde à

25. agir de façon responsable envers les autres. ______
26. être apprécié(e) des autres. ______
27. m'entendre avec ma famille. ______
28. avoir une copine ou un copain (blonde / chum). ______
29. faire des fêtes et avoir des choses à faire. ______
30. aux amis(es) que j'ai. ______

COMMUNAUTÉ : Mon accès aux choses

Quelle est l'importance que j'accorde à

31. être capable d'aller chercher des services médicaux et sociaux tout(e) seul(e). ______
32. recevoir une bonne éducation. ______
33. avoir assez d'argent. ______
34. avoir des emplois disponibles pendant que je fréquente encore l'école. ______
35. avoir des endroits où aller avec mes amis. ______
36. avoir des choses à faire dans ma communauté dans mon temps libre. ______

ÉCHELLE D'APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			S ans objet : SO	

Confidentiel 2012-12-31 15

DEVENIR **IMPORTANCE**

PRATIQUE : Les choses quotidiennes que je fais

Quelle est l'importance que j'accorde à

37. faire du travail bénévole pour les autres. ______
38. prendre soin de mon apparence et de mon hygiène. ______
39. étudier et à faire mes devoirs. ______
40. aux tâches que je fais à la maison. ______
41. aux choses que je fais à l'école. ______
42. au travail que je fais dans mon emploi, pendant que je fréquente encore l'école. ______

LOISIRS : Les choses que je fais pour le plaisir

Quelle est l'importance que j'accorde à

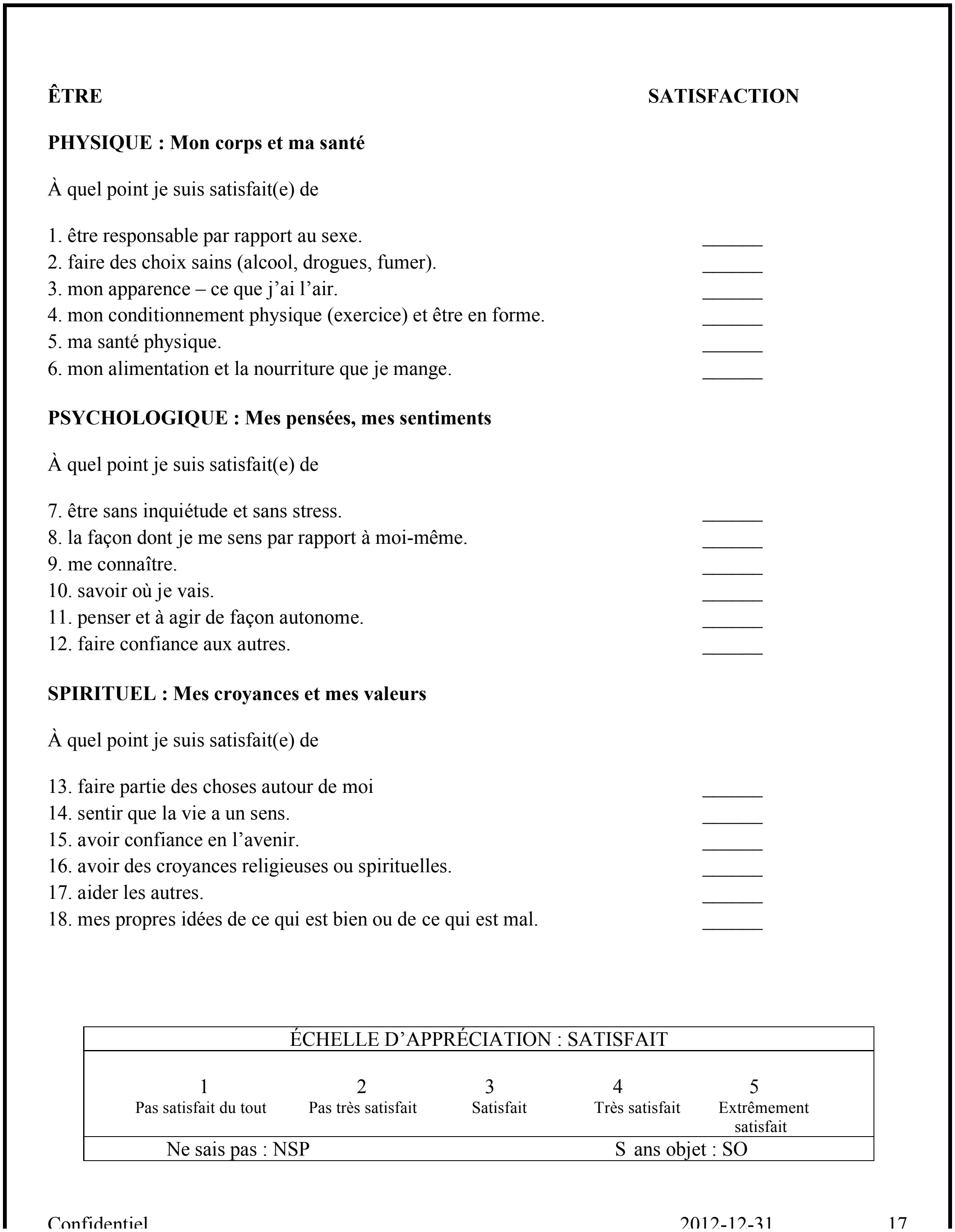
43. assister à des activités de divertissement publiques. ______
44. avoir des passe-temps et des intérêts personnels. ______
45. des activités intérieures (ex. lecture, télévision, etc.). ______
46. des activités à l'intérieur (ex. marche, bicyclette, etc.). ______
47. participer à des sports et à des activités récréatives. ______
48. visiter et à passer du temps avec les autres. ______

DÉVELOPPEMENT : Les choses que je fais pour m'améliorer et changer.

Quelle est l'importance que j'accorde à

49. réussir dans les choses que je fais. ______
50. m'entendre mieux avec les autres. ______
51. apprendre de nouvelles choses. ______
52. planifier en vue d'un emploi ou d'une carrière. ______
53. planifier en vue d'une éducation ou d'une formation. ______
54. résoudre mes problèmes. ______

ÉCHELLE D'APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			S ans objet : SO	



ÊTRE **SATISFACTION**

PHYSIQUE : Mon corps et ma santé

À quel point je suis satisfait(e) de

1. être responsable par rapport au sexe. ______
2. faire des choix sains (alcool, drogues, fumer). ______
3. mon apparence – ce que j'ai l'air. ______
4. mon conditionnement physique (exercice) et être en forme. ______
5. ma santé physique. ______
6. mon alimentation et la nourriture que je mange. ______

PSYCHOLOGIQUE : Mes pensées, mes sentiments

À quel point je suis satisfait(e) de

7. être sans inquiétude et sans stress. ______
8. la façon dont je me sens par rapport à moi-même. ______
9. me connaître. ______
10. savoir où je vais. ______
11. penser et à agir de façon autonome. ______
12. faire confiance aux autres. ______

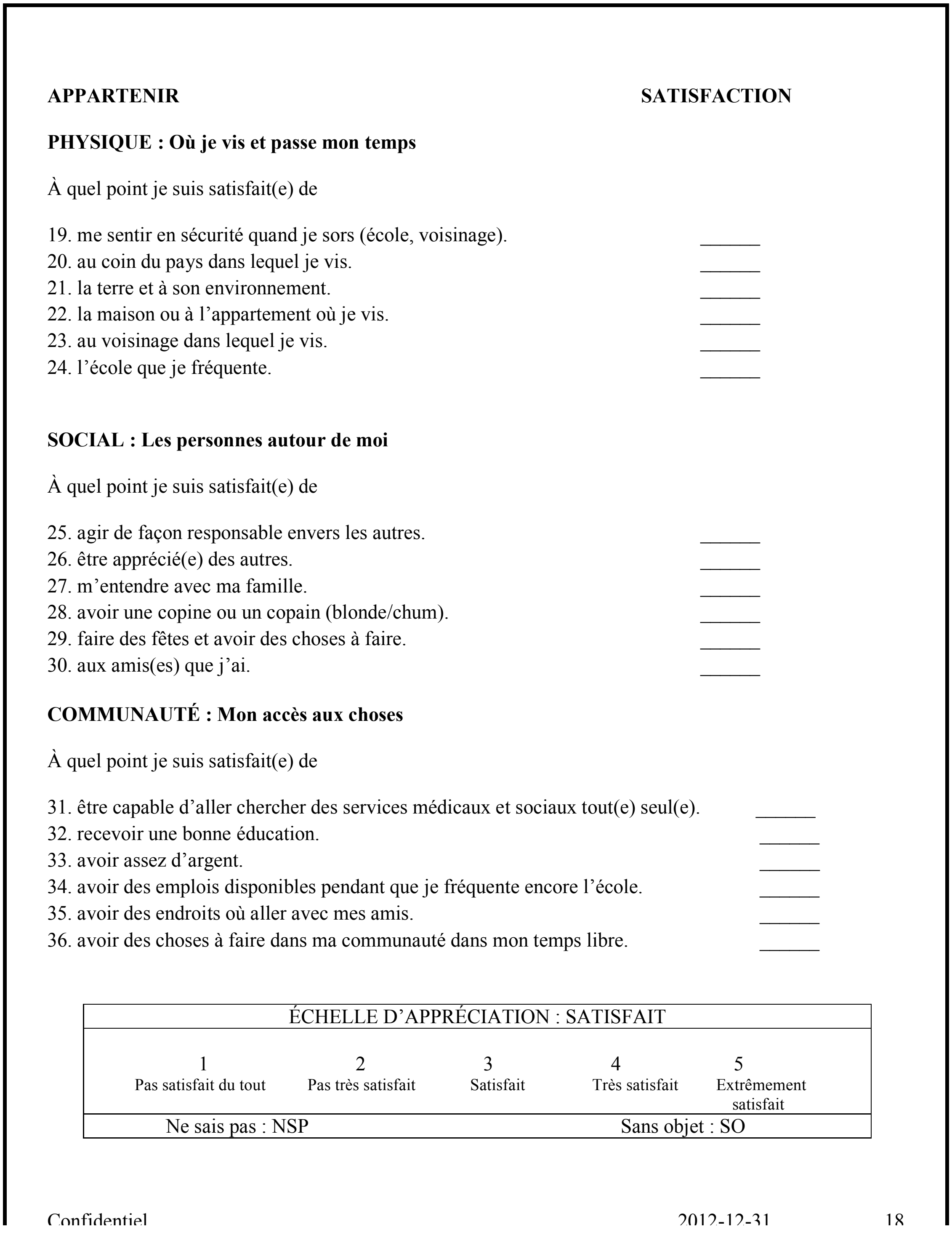
SPIRITUEL : Mes croyances et mes valeurs

À quel point je suis satisfait(e) de

13. faire partie des choses autour de moi ______
14. sentir que la vie a un sens. ______
15. avoir confiance en l'avenir. ______
16. avoir des croyances religieuses ou spirituelles. ______
17. aider les autres. ______
18. mes propres idées de ce qui est bien ou de ce qui est mal. ______

ÉCHELLE D'APPRÉCIATION : SATISFAIT				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			S ans objet : SO	

Confidentiel 2012-12-31 17



APPARTENIR **SATISFACTION**

PHYSIQUE : Où je vis et passe mon temps

À quel point je suis satisfait(e) de

19. me sentir en sécurité quand je sors (école, voisinage). ______
20. au coin du pays dans lequel je vis. ______
21. la terre et à son environnement. ______
22. la maison ou à l’appartement où je vis. ______
23. au voisinage dans lequel je vis. ______
24. l’école que je fréquente. ______

SOCIAL : Les personnes autour de moi

À quel point je suis satisfait(e) de

25. agir de façon responsable envers les autres. ______
26. être apprécié(e) des autres. ______
27. m’entendre avec ma famille. ______
28. avoir une copine ou un copain (blonde/chum). ______
29. faire des fêtes et avoir des choses à faire. ______
30. aux amis(es) que j’ai. ______

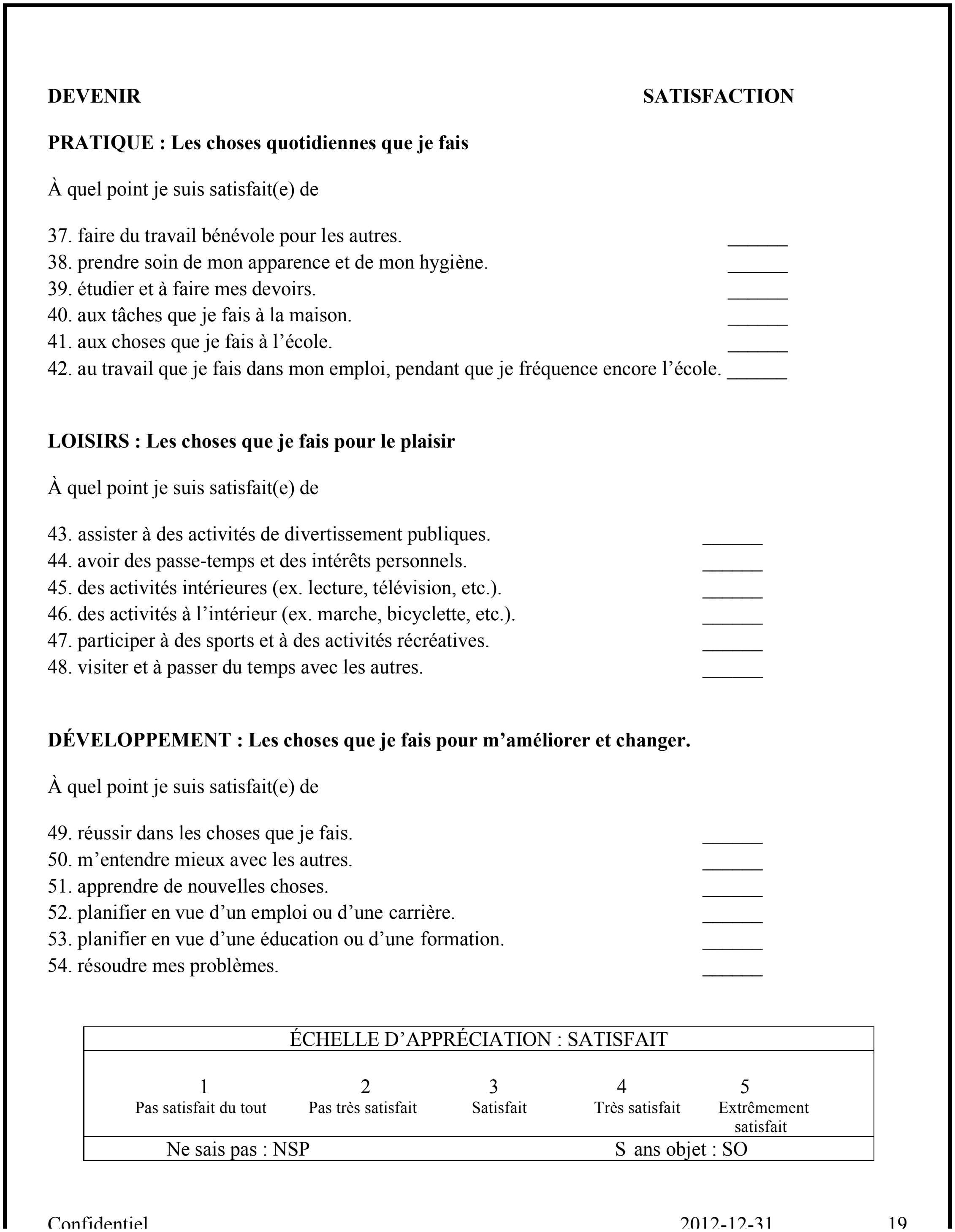
COMMUNAUTÉ : Mon accès aux choses

À quel point je suis satisfait(e) de

31. être capable d’aller chercher des services médicaux et sociaux tout(e) seul(e). ______
32. recevoir une bonne éducation. ______
33. avoir assez d’argent. ______
34. avoir des emplois disponibles pendant que je fréquente encore l’école. ______
35. avoir des endroits où aller avec mes amis. ______
36. avoir des choses à faire dans ma communauté dans mon temps libre. ______

ÉCHELLE D’APPRÉCIATION : SATISFAIT				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			Sans objet : SO	

Confidentiel 2012-12-31 18



DEVENIR **SATISFACTION**

PRATIQUE : Les choses quotidiennes que je fais

À quel point je suis satisfait(e) de

37. faire du travail bénévole pour les autres. ______
38. prendre soin de mon apparence et de mon hygiène. ______
39. étudier et à faire mes devoirs. ______
40. aux tâches que je fais à la maison. ______
41. aux choses que je fais à l'école. ______
42. au travail que je fais dans mon emploi, pendant que je fréquence encore l'école. ______

LOISIRS : Les choses que je fais pour le plaisir

À quel point je suis satisfait(e) de

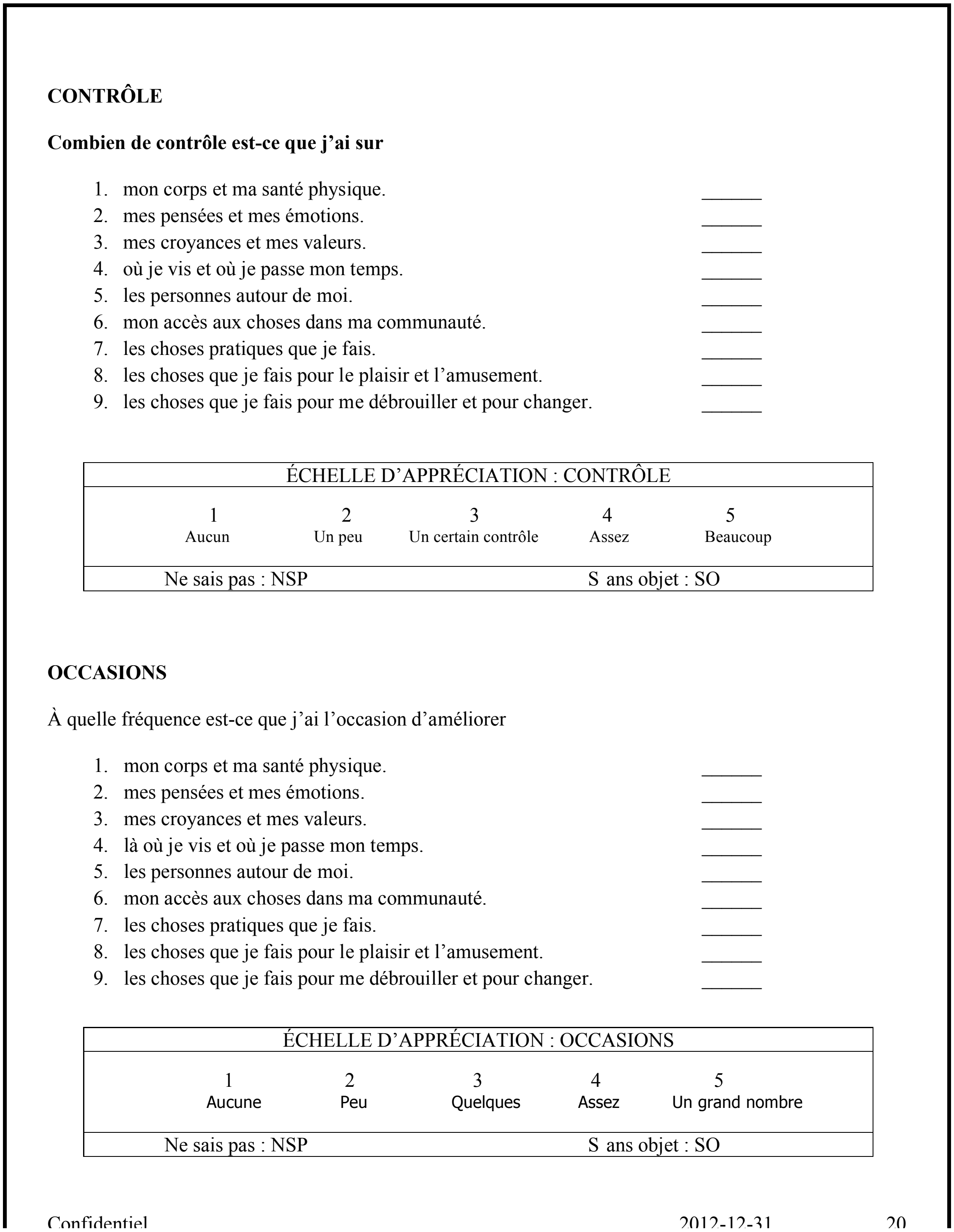
43. assister à des activités de divertissement publiques. ______
44. avoir des passe-temps et des intérêts personnels. ______
45. des activités intérieures (ex. lecture, télévision, etc.). ______
46. des activités à l'intérieur (ex. marche, bicyclette, etc.). ______
47. participer à des sports et à des activités récréatives. ______
48. visiter et à passer du temps avec les autres. ______

DÉVELOPPEMENT : Les choses que je fais pour m'améliorer et changer.

À quel point je suis satisfait(e) de

49. réussir dans les choses que je fais. ______
50. m'entendre mieux avec les autres. ______
51. apprendre de nouvelles choses. ______
52. planifier en vue d'un emploi ou d'une carrière. ______
53. planifier en vue d'une éducation ou d'une formation. ______
54. résoudre mes problèmes. ______

ÉCHELLE D'APPRÉCIATION : SATISFAIT				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			S ans objet : SO	



CONTRÔLE

Combien de contrôle est-ce que j'ai sur

1. mon corps et ma santé physique. ______
2. mes pensées et mes émotions. ______
3. mes croyances et mes valeurs. ______
4. où je vis et où je passe mon temps. ______
5. les personnes autour de moi. ______
6. mon accès aux choses dans ma communauté. ______
7. les choses pratiques que je fais. ______
8. les choses que je fais pour le plaisir et l'amusement. ______
9. les choses que je fais pour me débrouiller et pour changer. ______

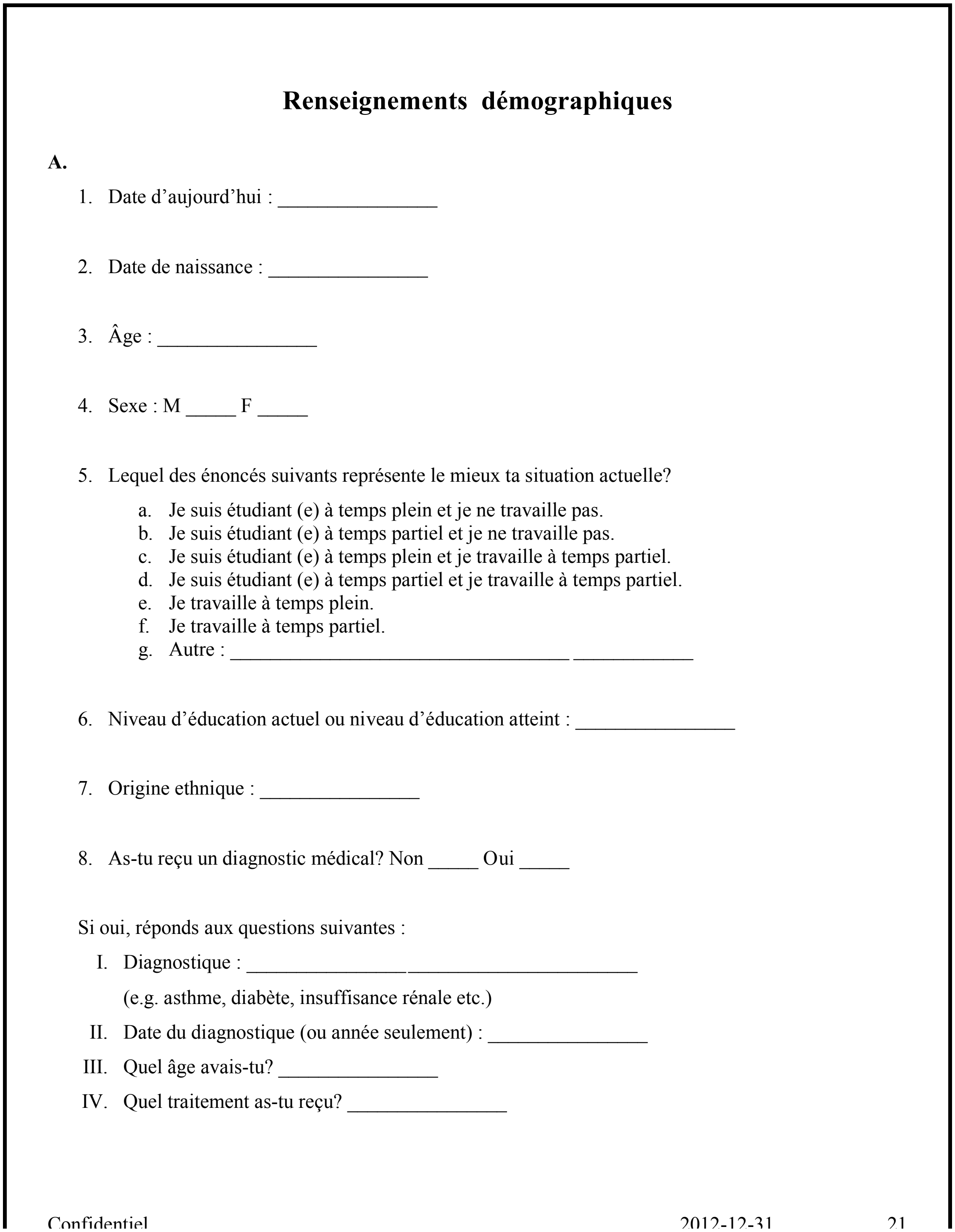
ÉCHELLE D'APPRÉCIATION : CONTRÔLE				
1 Aucun	2 Un peu	3 Un certain contrôle	4 Assez	5 Beaucoup
Ne sais pas : NSP			Sans objet : SO	

OCCASIONS

À quelle fréquence est-ce que j'ai l'occasion d'améliorer

1. mon corps et ma santé physique. ______
2. mes pensées et mes émotions. ______
3. mes croyances et mes valeurs. ______
4. là où je vis et où je passe mon temps. ______
5. les personnes autour de moi. ______
6. mon accès aux choses dans ma communauté. ______
7. les choses pratiques que je fais. ______
8. les choses que je fais pour le plaisir et l'amusement. ______
9. les choses que je fais pour me débrouiller et pour changer. ______

ÉCHELLE D'APPRÉCIATION : OCCASIONS				
1 Aucune	2 Peu	3 Quelques	4 Assez	5 Un grand nombre
Ne sais pas : NSP			Sans objet : SO	



Renseignements démographiques

A.

1. Date d’aujourd’hui : ________________

2. Date de naissance : ________________

3. Âge : ________________

4. Sexe : M _____ F _____

5. Lequel des énoncés suivants représente le mieux ta situation actuelle?
    a. Je suis étudiant (e) à temps plein et je ne travaille pas.
    b. Je suis étudiant (e) à temps partiel et je ne travaille pas.
    c. Je suis étudiant (e) à temps plein et je travaille à temps partiel.
    d. Je suis étudiant (e) à temps partiel et je travaille à temps partiel.
    e. Je travaille à temps plein.
    f. Je travaille à temps partiel.
    g. Autre : __________________________________ ____________

6. Niveau d’éducation actuel ou niveau d’éducation atteint : ________________

7. Origine ethnique : ________________

8. As-tu reçu un diagnostic médical? Non _____ Oui _____

Si oui, réponds aux questions suivantes :

I. Diagnostique : ____
(e.g. asthme, diabète, insuffisance rénale etc.)
II. Date du diagnostique (ou année seulement) : ________________
III. Quel âge avais-tu? ________________
IV. Quel traitement as-tu reçu? ________________

9. Présentement, prends-tu des médicaments? Non ___ Oui ___

10. Si oui, quels médicaments prends-tu?

____

____

___________________________ ____

____

____

11. As-tu vécu des changements importants dans la dernière année? (Exemple : déménagement, changement d'école, décès, arrêt d'éducation, etc.)?

____

____ _________________________

____

____

B.

I. Présentement, habites-tu chez tes parents? Non ___ Oui ___

II. Tes parents sont-ils :

a. Mariés
b. Divorcés (si oui, depuis quand? ______)
c. Séparés (si oui, depuis quand? ______)
d. Autre

III. As-tu des frères et sœurs? Non ___ Oui ___

Si oui, combien? _______

IV. Quelle est :

a. L'occupation de ta mère? _________________

b. L'occupation de ton père? _________________

V. Quel est le plus haut niveau d'éducation de ta mère?

a. Secondaire
b. C.E.G.E.P
c. Université - Études supérieures
d. Je ne sais pas.

VI. Quel est le plus haut niveau d'éducation de ton père?

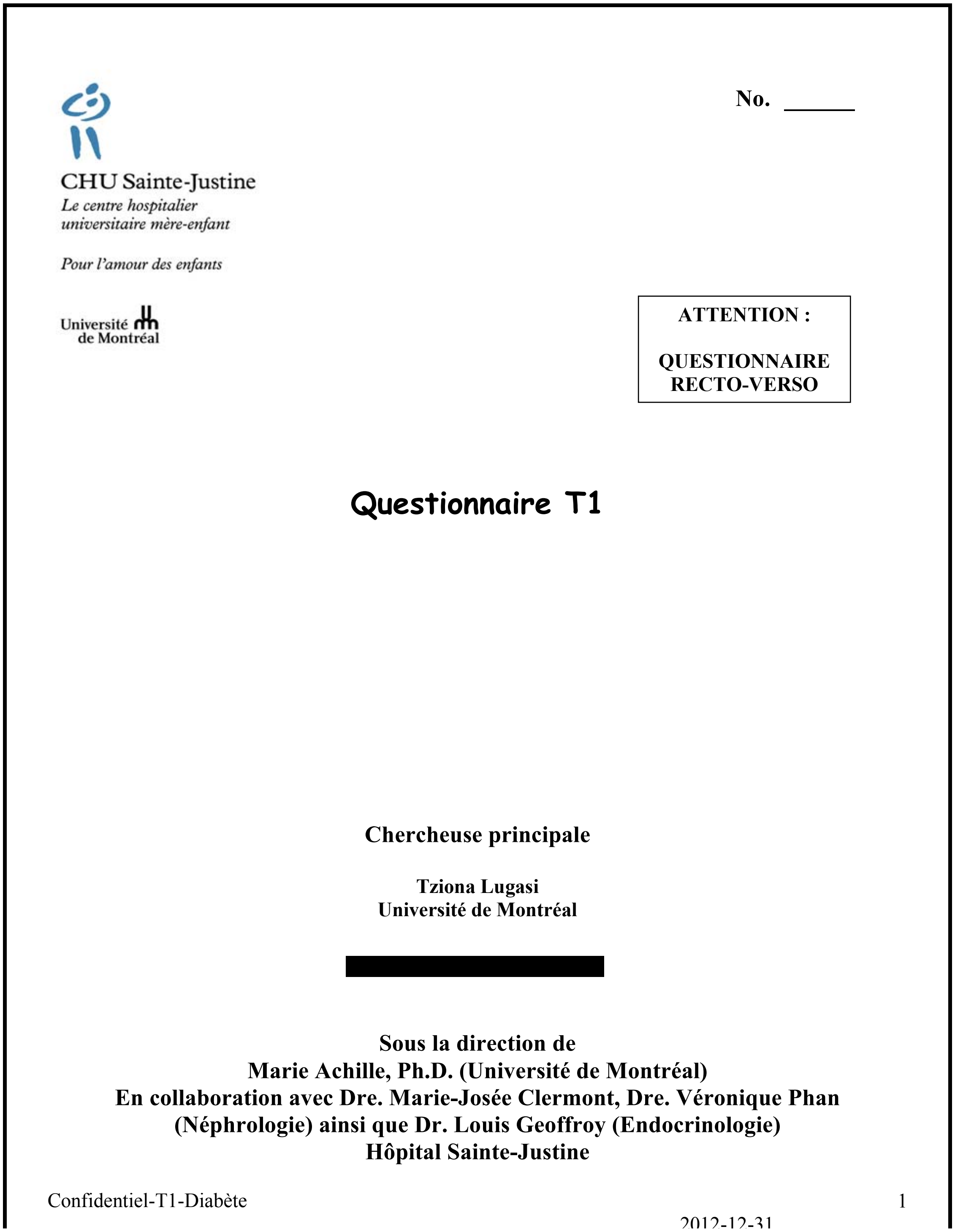
a. Secondaire
b. C.E.G.E.P
c. Université - Études supérieures
d. Je ne sais pas.

VII. Quel est le revenu annuel de ta famille?

a. Moins de 10 000 $
b. 10 000 - 19 999 $
c. 20 000 - 34 999 $
d. 35 000 - 49 999 $
e. 50 000 - 74 999 $
f. 75 000 - 99 999 $
g. Plus de 100 000 $
h. Je ne sais pas.

Annexe I

Questionnaire Temps 1-patients



CHU Sainte-Justine
Le centre hospitalier
universitaire mère-enfant

Pour l'amour des enfants

Université de Montréal

No. ______

ATTENTION :

QUESTIONNAIRE RECTO-VERSO

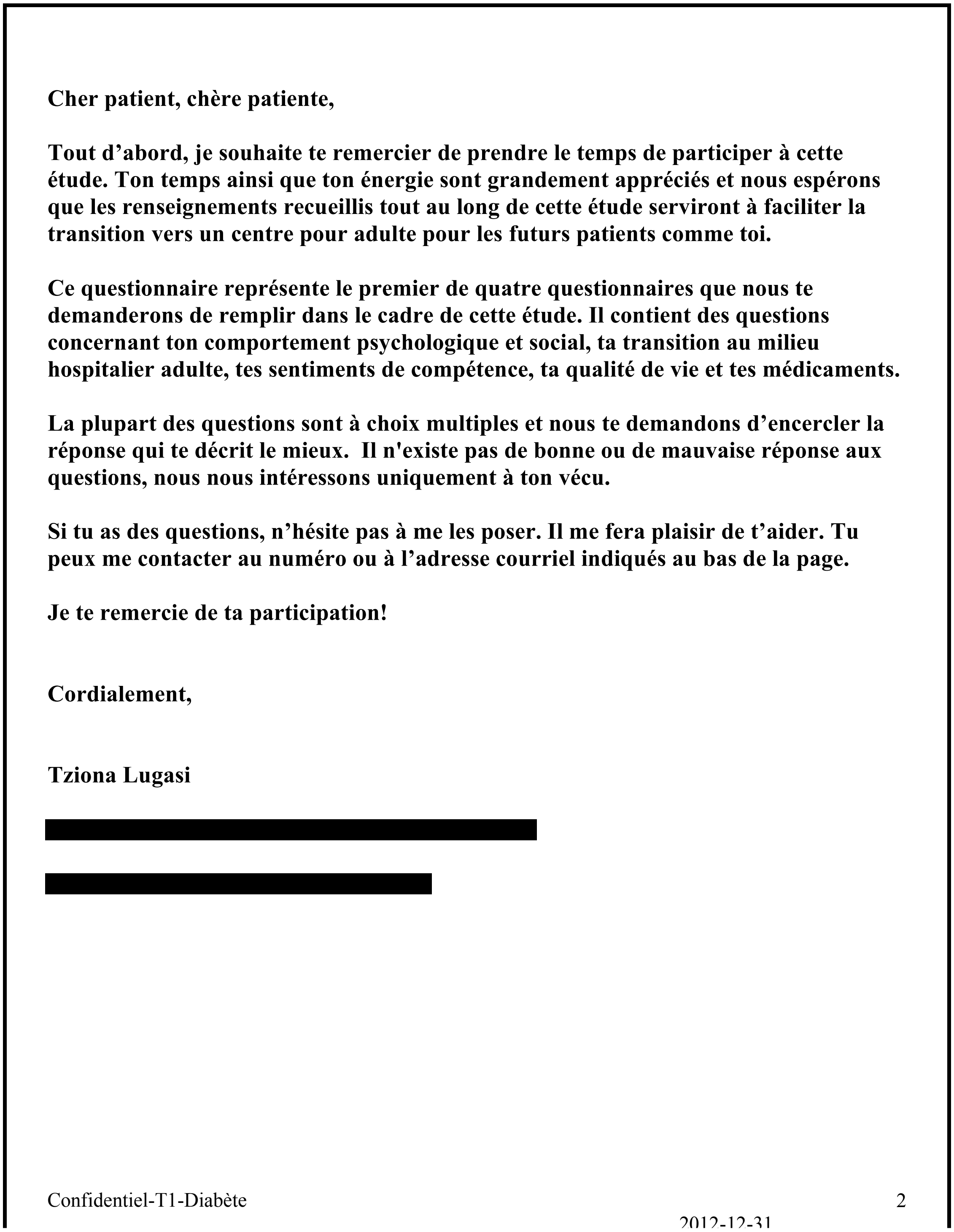
Questionnaire T1

Chercheuse principale

Tziona Lugasi
Université de Montréal

[redacted]

Sous la direction de
Marie Achille, Ph.D. (Université de Montréal)
En collaboration avec Dre. Marie-Josée Clermont, Dre. Véronique Phan (Néphrologie) ainsi que Dr. Louis Geoffroy (Endocrinologie)
Hôpital Sainte-Justine



Cher patient, chère patiente,

Tout d'abord, je souhaite te remercier de prendre le temps de participer à cette étude. Ton temps ainsi que ton énergie sont grandement appréciés et nous espérons que les renseignements recueillis tout au long de cette étude serviront à faciliter la transition vers un centre pour adulte pour les futurs patients comme toi.

Ce questionnaire représente le premier de quatre questionnaires que nous te demanderons de remplir dans le cadre de cette étude. Il contient des questions concernant ton comportement psychologique et social, ta transition au milieu hospitalier adulte, tes sentiments de compétence, ta qualité de vie et tes médicaments.

La plupart des questions sont à choix multiples et nous te demandons d'encercler la réponse qui te décrit le mieux. Il n'existe pas de bonne ou de mauvaise réponse aux questions, nous nous intéressons uniquement à ton vécu.

Si tu as des questions, n'hésite pas à me les poser. Il me fera plaisir de t'aider. Tu peux me contacter au numéro ou à l'adresse courriel indiqués au bas de la page.

Je te remercie de ta participation!

Cordialement,

Tziona Lugasi

[redacted]

Questionnaire DTQ

Il y a un bon nombre de buts et de besoins qui peuvent être importants pour les adolescents de ton âge. Nous voulons savoir quels sont les besoins que tu crois avoir satisfaits, quels sont les buts que tu crois avoir déjà atteints et à quel point ces buts et besoins sont importants pour toi dans le futur. Indique ta réponse en utilisant l'échelle appropriée pour chaque question.

1. Appartiens-tu présentement à un groupe de pairs (d'amis)?	1 Pas encore	2 Commence tout juste	3 Déjà développé
A. À quel point est-ce important pour toi, dans le futur, d'appartenir à un groupe de pairs (d'amis)?	1 Pas important du tout	2 Assez important	3 Très important

2. Filles : As-tu déjà eu tes premières règles?	1 Pas encore	2 Commence tout juste	3 Déjà développé
B. Filles : À quel point est-ce important (ou est-ce que c'était important) pour toi d'avoir tes premières règles bientôt?	1 Pas important du tout	2 Assez important	3 Très important

2. Garçons : As-tu commencé à te raser?	1 Pas encore	2 Commence tout juste	3 Déjà développé
B. Garçons : À quel point est-ce important (ou est-ce que c'était important) pour toi de te raser bientôt?	1 Pas important du tout	2 Assez important	3 Très important

3. As-tu développé ta propre identité?	1 Pas encore	2 Commence tout juste	3 Déjà développé
C. À quel point est-ce important pour toi, dans le futur, de développer ta propre identité ?	1 Pas important du tout	2 Assez important	3 Très important

4. Penses-tu que tu te tiens debout (que tu es indépendant(e))?	1 Pas encore	2 Commence tout juste	3 Déjà développé

D. À quel point est-il important pour toi, dans le futur, de te tenir debout (d'être indépendant(e))?	1 Pas important du tout	2 Assez important	3 Très important

5. As-tu présentement les habiletés nécessaires pour élever un enfant?	1 Pas encore	2 Commence tout juste	3 Déjà développé
E. À quel point est-ce important pour toi, dans le futur, de développer ces habiletés?	1 Pas important du tout	2 Assez important	3 Très important

6. Sais-tu comment notre pays est gouverné?	1 Pas encore	2 Commence tout juste	3 Déjà développé
F. À quel point est-ce important pour toi, dans le futur, de savoir comment notre pays est gouverné?	1 Pas important du tout	2 Assez important	3 Très important

7. Crois-tu que tu es préparé(e) pour l'emploi que tu désires?	1 Pas encore	2 Commence tout juste	3 Déjà développé
G. À quel point est-ce important pour toi, dans le futur, d'être préparé(e) pour l'emploi que tu désires?	1 Pas important du tout	2 Assez important	3 Très important

8. As-tu une perception réaliste de toi-même?	1 Pas encore	2 Commence tout juste	3 Déjà développé
H. À quel point est-ce important pour toi, dans le futur, d'avoir une perception réaliste de toi-même?	1 Pas important du tout	2 Assez important	3 Très important

9. Présentement, as-tu un style de vie personnel en ce qui a trait à l'habillement, au comportement, aux passe-temps et aux activités sociales?	1 Pas encore	2 Commence tout juste	3 Déjà développé
I. À quel point est-ce important pour toi, dans le futur, d'avoir un style de vie personnel?	1 Pas important du tout	2 Assez important	3 Très important

10. Es-tu présentement amoureux(se) d'un garçon / d'une fille?	1 Pas encore 2 Commence tout juste 3 Déjà développé
J. À quel point est-ce important pour toi, dans le futur, de tomber amoureux(se) d'un garçon / d'une fille?	1 Pas important du tout 2 Assez important 3 Très important

11. Fille : Présentement, as-tu une amie à qui tu peux parler de tout? Garçon : Présentement as-tu un ami à qui tu peux parler de tout	1 Pas encore 2 Commence tout juste 3 Déjà développé
K. À quel point est-ce important pour toi, dans le futur, d'avoir un tel ami / une telle amie?	1 Pas important du tout 2 Assez important 3 Très important

Questionnaire EOMEIS-2

Lis chaque question et encercle la réponse qui s'applique à toi.

1 = fortement en désaccord (-)	**4 = partiellement d'accord**
2 = en désaccord	**5 = d'accord**
3 = partiellement en désaccord	**6 = fortement d'accord (+)**

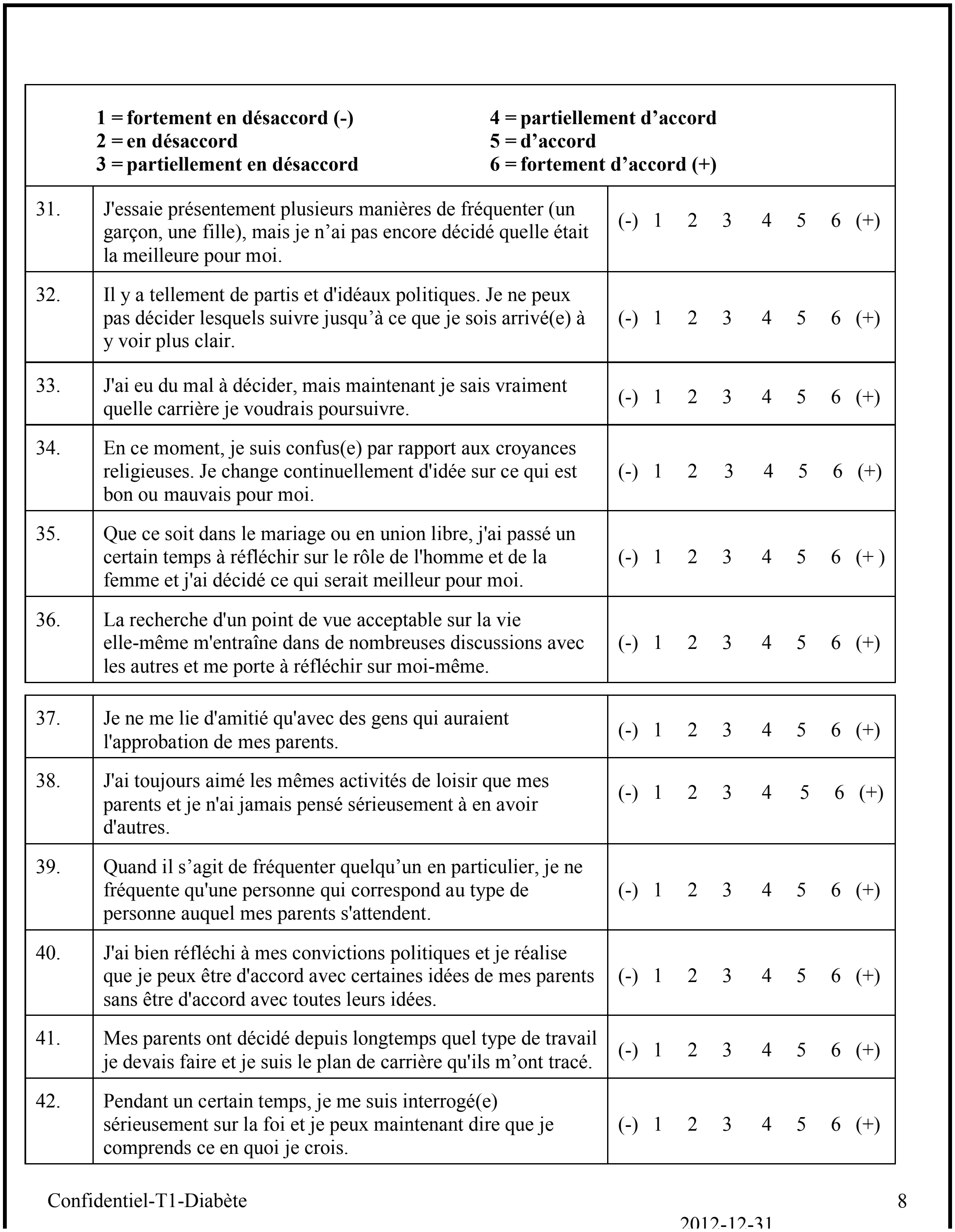
1.	Je n'ai pas choisi l'emploi que je veux réellement occuper et je fais n'importe quel travail que je trouve en attendant mieux.	(-) 1 2 3 4 5 6 (+)
2.	En ce qui concerne les croyances religieuses, je n'ai simplement rien trouvé qui me tente et je ne ressens pas véritablement le besoin de chercher.	(-) 1 2 3 4 5 6 (+)
3.	Mes idées sur le rôle respectif de l'homme et de la femme sont les mêmes que celles de mes parents. Ce qui a bien marché pour eux marchera évidemment pour moi.	(-) 1 2 3 4 5 6 (+)
4.	Je n'ai pas de préférences pour un style de vie particulier plutôt qu'un autre.	(-) 1 2 3 4 5 6 (+)
5.	Il y a des gens de toutes sortes. J'en suis encore à explorer les nombreuses possibilités afin de trouver le bon type d'ami pour moi.	(-) 1 2 3 4 5 6 (+)
6.	Je m'implique parfois dans des passe-temps ou des activités récréatives lorsqu'on me le demande, mais j'essaie rarement quoi que ce soit par moi-même.	(-) 1 2 3 4 5 6 (+)

1 = fortement en désaccord (-)
2 = en désaccord
3 = partiellement en désaccord

4 = partiellement d'accord
5 = d'accord
6 = fortement d'accord (+)

7.	Je n'ai pas véritablement pensé à un «style de fréquentation». Fréquenter quelqu'un en particulier ou pas n'a pas grande importance pour moi.	(-) 1 2 3 4 5 6 (+)
8.	Je ne peux jamais être très certain(e) en politique parce que tout change si rapidement. Par contre, je pense que c'est important de savoir quelles idées je suis prêt(e) à défendre et auxquelles je crois.	(-) 1 2 3 4 5 6 (+)
9.	J'en suis encore à évaluer ce dont je suis capable et quel type de travail me conviendrait.	(-) 1 2 3 4 5 6 (+)
10.	La question des croyances religieuses est un sujet auquel je ne pense pas beaucoup et cela ne me gêne pas.	(-) 1 2 3 4 5 6 (+)
11.	Que ce soit dans le mariage ou en union libre, il y a tellement de façons de répartir les responsabilités. J'essaie de trouver ce qui pourrait me convenir.	(-) 1 2 3 4 5 6 (+)
12.	Je suis à la recherche d'un point de vue acceptable à partir duquel considérer mon style de vie, mais je ne l'ai pas encore trouvé.	(-) 1 2 3 4 5 6 (+)
13.	L'amitié peut être fondée sur de nombreuses raisons, mais je choisis mes amis intimes en fonction de certaines valeurs et de points communs sur lesquels j'ai bien réfléchi.	(-) 1 2 3 4 5 6 (+)
14.	Je n'ai aucune activité récréative dans laquelle je suis vraiment engagé(e), mais j'expérimente différentes formes de loisirs afin d'en trouver une dans laquelle je peux vraiment m'impliquer.	(-) 1 2 3 4 5 6 (+)
15.	C'est en m'appuyant sur mes expériences passées que j'ai choisi le type de fréquentation que je veux maintenant.	(-) 1 2 3 4 5 6 (+)
16.	Je n'ai pas réellement pensé à la politique; ça ne m'intéresse pas beaucoup.	(-) 1 2 3 4 5 6 (+)
17.	J'aurais pu penser à de nombreuses manières de gagner ma vie, mais je ne me suis jamais vraiment questionné(e) à ce sujet étant donné que mes parents ont exprimé ce qu'ils attendaient de moi.	(-) 1 2 3 4 5 6 (+)
18.	La foi d'une personne est une chose vraiment personnelle. J'y ai pensé et repensé et je sais ce en quoi je peux croire.	(-) 1 2 3 4 5 6 (+)

	1 = fortement en désaccord (-) **2 = en désaccord** **3 = partiellement en désaccord**	**4 = partiellement d'accord** **5 = d'accord** **6 = fortement d'accord (+)**
19.	Je n'ai jamais pensé sérieusement au rôle de la femme et de l'homme, que ce soit dans le mariage ou en union libre. Je ne vois pas en quoi cela me concerne.	(-) 1 2 3 4 5 6 (+)
20.	Après y avoir beaucoup pensé, je me suis fait ma propre opinion sur ce que peut être le mode de vie idéal pour moi et je pense que personne ne pourra un jour me faire changer d'idée.	(-) 1 2 3 4 5 6 (+)
21.	Mes parents savent mieux que moi ce qui est le mieux pour moi en ce qui a trait à choisir mes amis.	(-) 1 2 3 4 5 6 (+)
22.	J'ai choisi un ou plusieurs passe-temps ou activités récréatives que je pratique régulièrement; mon choix a été fait après avoir examiné de nombreuses possibilités et je suis content(e) de ce choix.	(-) 1 2 3 4 5 6 (+)
23.	Je ne pense pas beaucoup à sortir avec quelqu'un en particulier. Je profite simplement des occasions qui passent.	(-) 1 2 3 4 5 6 (+)
24.	Je pense que mes opinions politiques sont en gros celles de ma famille. Je fais comme eux quand vient le temps de voter ou autre.	(-) 1 2 3 4 5 6 (+)
25.	Trouver l'emploi idéal ne m'intéresse pas vraiment; n'importe quel travail fera l'affaire. Je semble prendre ce qui est disponible.	(-) 1 2 3 4 5 6 (+)
26.	Je ne sais pas au juste ce que signifie pour moi avoir des croyances religieuses. Je voudrais bien me décider, mais je cherche encore.	(-) 1 2 3 4 5 6 (+)
27.	Mes idées sur le rôle de l'homme et de la femme me viennent directement de ma famille et de mes parents. Je n'ai pas senti le besoin d'aller chercher ailleurs.	(-) 1 2 3 4 5 6 (+)
28.	Mes idées sur le style de vie que je voudrais m'ont été inculquées par mes parents et je ne vois pas la nécessité de remettre en question ce qu'ils m'ont enseigné.	(-) 1 2 3 4 5 6 (+)
29.	Je n'ai pas véritablement d'amis intimes et je ne pense pas que je cherche à en avoir en ce moment.	(-) 1 2 3 4 5 6 (+)
30.	Je participe parfois à des activités de loisir, mais je ne vois vraiment pas le besoin de me chercher une activité de loisir régulière.	(-) 1 2 3 4 5 6 (+)



1 = fortement en désaccord (-) **4 = partiellement d’accord**
2 = en désaccord **5 = d’accord**
3 = partiellement en désaccord **6 = fortement d’accord (+)**

31.	J'essaie présentement plusieurs manières de fréquenter (un garçon, une fille), mais je n’ai pas encore décidé quelle était la meilleure pour moi.	(-) 1 2 3 4 5 6 (+)
32.	Il y a tellement de partis et d'idéaux politiques. Je ne peux pas décider lesquels suivre jusqu’à ce que je sois arrivé(e) à y voir plus clair.	(-) 1 2 3 4 5 6 (+)
33.	J'ai eu du mal à décider, mais maintenant je sais vraiment quelle carrière je voudrais poursuivre.	(-) 1 2 3 4 5 6 (+)
34.	En ce moment, je suis confus(e) par rapport aux croyances religieuses. Je change continuellement d'idée sur ce qui est bon ou mauvais pour moi.	(-) 1 2 3 4 5 6 (+)
35.	Que ce soit dans le mariage ou en union libre, j'ai passé un certain temps à réfléchir sur le rôle de l'homme et de la femme et j'ai décidé ce qui serait meilleur pour moi.	(-) 1 2 3 4 5 6 (+)
36.	La recherche d'un point de vue acceptable sur la vie elle-même m'entraîne dans de nombreuses discussions avec les autres et me porte à réfléchir sur moi-même.	(-) 1 2 3 4 5 6 (+)
37.	Je ne me lie d'amitié qu'avec des gens qui auraient l'approbation de mes parents.	(-) 1 2 3 4 5 6 (+)
38.	J'ai toujours aimé les mêmes activités de loisir que mes parents et je n'ai jamais pensé sérieusement à en avoir d'autres.	(-) 1 2 3 4 5 6 (+)
39.	Quand il s’agit de fréquenter quelqu’un en particulier, je ne fréquente qu'une personne qui correspond au type de personne auquel mes parents s'attendent.	(-) 1 2 3 4 5 6 (+)
40.	J'ai bien réfléchi à mes convictions politiques et je réalise que je peux être d'accord avec certaines idées de mes parents sans être d'accord avec toutes leurs idées.	(-) 1 2 3 4 5 6 (+)
41.	Mes parents ont décidé depuis longtemps quel type de travail je devais faire et je suis le plan de carrière qu'ils m’ont tracé.	(-) 1 2 3 4 5 6 (+)
42.	Pendant un certain temps, je me suis interrogé(e) sérieusement sur la foi et je peux maintenant dire que je comprends ce en quoi je crois.	(-) 1 2 3 4 5 6 (+)

1 = fortement en désaccord (-) **4 = partiellement d’accord**
2 = en désaccord **5 = d’accord**
3 = partiellement en désaccord **6 = fortement d’accord (+)**

43.	Que ce soit dans le mariage ou en union libre, j'ai beaucoup pensé ces derniers temps au rôle que jouent les hommes et les femmes et j’essaie de me faire une idée définitive.	(-) 1 2 3 4 5 6 (+)
44.	Les opinions des mes parents sur la vie me suffisent et je n'ai besoin de rien d'autre.	(-) 1 2 3 4 5 6 (+)
45.	J'ai essayé de nombreuses formes d'amitié et je sais maintenant ce que j'attends d'un ami.	(-) 1 2 3 4 5 6 (+)
46.	Après avoir essayé de nombreux hobbys et passe-temps, j'en ai trouvé un ou plusieurs que j'aime faire, seul(e) ou avec des ami(e)s.	(-) 1 2 3 4 5 6 (+)
47.	Je suis encore en train de développer mes préférences en ce qui concerne ma manière de fréquenter quelqu’un. Je ne suis pas encore complètement décidé(e).	(-) 1 2 3 4 5 6 (+)
48.	Je ne suis pas sûr(e) de mes convictions politiques, mais j’essaie de trouver ce en quoi je peux vraiment croire.	(-) 1 2 3 4 5 6 (+)
49.	J'ai mis longtemps à me décider, mais maintenant je suis certain(e) de la direction que je veux prendre pour ma carrière.	(-) 1 2 3 4 5 6 (+)
50.	J'ai les mêmes croyances que mes parents en ce qui concerne la religion. Je ne me suis jamais demandé(e) pourquoi.	(-) 1 2 3 4 5 6 (+)
51.	Que ce soit dans le mariage ou en union libre, les couples peuvent se répartir les responsabilités familiales de nombreuses façons. J'ai pensé à de nombreuses options et je sais maintenant exactement comment je voudrais que cela se passe pour moi.	(-) 1 2 3 4 5 6 (+)
52.	J’ai l’impression que je profite de la vie en général et je ne vois pas la nécessité pour moi d'adopter une philosophie de vie particulière.	(-) 1 2 3 4 5 6 (+)
53.	Je n'ai pas d'ami(e) intime. J'aime simplement me retrouver avec les copains / copines.	(-) 1 2 3 4 5 6 (+)
54.	J’expérimente plusieurs activités de loisir dans l'espoir d'en trouver au moins une qui pourrait me plaire pendant un certain temps.	(-) 1 2 3 4 5 6 (+)

1 = fortement en désaccord (-) **4 = partiellement d'accord**
2 = en désaccord **5 = d'accord**
3 = partiellement en désaccord **6 = fortement d'accord (+)**

55.	J'ai fréquenté différents types de personnes et maintenant je sais exactement quelles sont mes propres « règles non écrites » pour les sorties et avec qui j'accepte de sortir.	(-) 1 2 3 4 5 6 (+)
56.	Je ne me suis jamais senti(e) suffisamment concerné(e) par la politique pour prendre position de manière ferme d'un côté ou de l'autre.	(-) 1 2 3 4 5 6 (+)
57.	Je n'arrive vraiment pas à décider de ce que je veux faire. Il y a tellement de choix de carrière.	(-) 1 2 3 4 5 6 (+)
58.	Je n'ai jamais vraiment mis en question mes croyances concernant la religion. Si elles sont bonnes pour mes parents, elles doivent être bonnes pour moi aussi.	(-) 1 2 3 4 5 6 (+)
59.	Les opinions par rapport aux hommes et aux femmes semblent si diversifiées que ça ne sert à rien pour moi de m'y attarder.	(-) 1 2 3 4 5 6 (+)
60.	Après m'être examiné(e) et interrogé(e) de manière approfondie, je me suis fait une opinion très nette de ce que devrait être mon style de vie.	(-) 1 2 3 4 5 6 (+)
61.	Je ne sais pas vraiment quel type d'ami serait le meilleur pour moi. J'essaie de trouver ce que veut vraiment dire l'amitié pour moi.	(-) 1 2 3 4 5 6 (+)
62.	Toutes mes préférences pour les activités de loisir me viennent de mes parents et je n'en ai pas vraiment essayé d'autres.	(-) 1 2 3 4 5 6 (+)
63.	Je ne fréquente que des personnes que mes parents approuveraient.	(-) 1 2 3 4 5 6 (+)
64.	Mes parents ont toujours eu leurs propres opinions politiques et morales sur des sujets tels que l'avortement et l'euthanasie et j'ai toujours accepté leur opinion.	(-) 1 2 3 4 5 6 (+)

A. Transition

Parfois, les adolescents et les parents ont des préoccupations ou des questions par rapport à comment ça sera de passer d'un programme de soins médicaux pédiatrique à un programme pour adultes. S'il te plaît, lis attentivement les questions suivantes et indique quelles préoccupations tu as par rapport à la transition à un programme de soins médicaux pour adultes.

	Pas du tout	**Un peu**	**Modérément**	**Beaucoup**
1. J'ai des préoccupations par rapport à ne pas avoir assez d'informations pour savoir à quoi m'attendre.	☐1	☐2	☐3	☐4
2. J'ai des préoccupations par rapport à si je vais devoir être responsable de moi-même.	☐1	☐2	☐3	☐4
3. J'ai des préoccupations par rapport à si je vais être capable de prendre des décisions seul(e).	☐1	☐2	☐3	☐4
4. J'ai des préoccupations par rapport à si je vais avoir de la difficulté à ce que le personnel médical me parle plutôt qu'à mes parents.	☐1	☐2	☐3	☐4
5. J'ai des préoccupations par rapport à si je vais savoir comment obtenir ou demander l'information dont j'ai besoin.	☐1	☐2	☐3	☐4
6. J'ai des préoccupations par rapport au fait d'être traité (e) comme un adulte.	☐1	☐2	☐3	☐4
7. Je ne suis pas préoccupé(e) par le fait de parler de ma santé à d'autres personnes.	☐1	☐2	☐3	☐4
8. Je suis préoccupé(e) quant à comment je vais faire les allers-retours pour me rendre à la clinique.	☐1	☐2	☐3	☐4
9. Je ne suis pas préoccupé(e) en ce qui concerne comment je vais payer mes soins médicaux.	☐1	☐2	☐3	☐4
10. Je suis préoccupé(e) par rapport au fait que mes parents vont me laisser ou non répondre aux questions du personnel médical ou parler au personnel médical moi-même.	☐1	☐2	☐3	☐4

	Pas du tout	**Un peu**	**Modérément**	**Beaucoup**
11. Je suis préoccupé(e) par rapport au fait que le personnel médical dans le milieu adulte pourrait ne pas me connaître et ne pas comprendre comment le diabète/insuffisance rénale fonctionne.	☐1	☐2	☐3	☐4
12. Je suis préoccupé(e) par le fait d'être perçu(e) comme quelqu'un qui recherche de la drogue lorsque je suis en douleur ou que j'ai besoin de médicaments.	☐1	☐2	☐3	☐4
13. Je ne veux pas quitter le personnel médical que je connais depuis très longtemps et qui me comprend.	☐1	☐2	☐3	☐4
14. J'ai peur d'apprendre à connaître un nouveau personnel médical.	☐1	☐2	☐3	☐4
15. J'ai peur que le nouveau personnel médical ne me croie pas.	☐1	☐2	☐3	☐4
Autres :				

B. Sentiments

Dis-nous comment tu te sens par rapport à ta transition à un milieu de soins pour adultes.

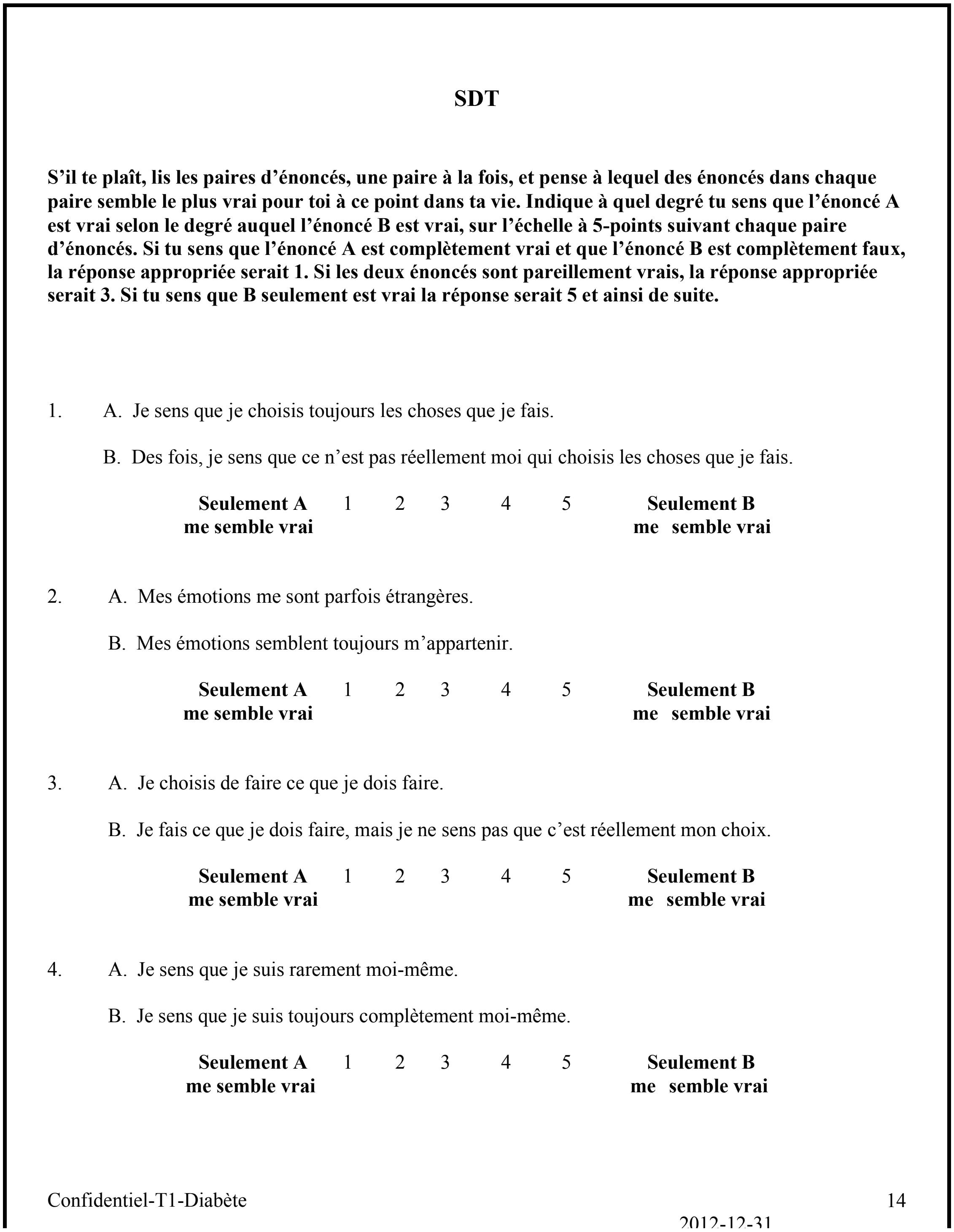
	Pas du tout	**Un peu**	**Modérément**	**Beaucoup**
1. Je suis excité(e) / content(e).	☐1	☐2	☐3	☐4
2. J'ai peur.	☐1	☐2	☐3	☐4
3. Je suis soulagé(e).	☐1	☐2	☐3	☐4
4. Je suis incertain(e).	☐1	☐2	☐3	☐4
5. Je n'ai pas de sentiment d'une façon ou de l'autre.	☐1	☐2	☐3	☐4
6. Je suis inquiet(iète).	☐1	☐2	☐3	☐4
7. Je suis nerveux(se).	☐1	☐2	☐3	☐4

	Pas du tout	**Un peu**	**Modérément**	**Beaucoup**
8. Je sens que c’est le bon moment de transférer (aux soins adultes).	☐1	☐2	☐3	☐4
9. Je suis anxieux(se).	☐1	☐2	☐3	☐4
10. L’idée me convient.	☐1	☐2	☐3	☐4
11. Je suis en colère.	☐1	☐2	☐3	☐4
12. Je me sens délaissé(e) et abandonné(e).	☐1	☐2	☐3	☐4
13. Je sens que je n’aie aucun contrôle sur la décision.	☐1	☐2	☐3	☐4
14. Autre(s) sentiment(s).				

C. Préparation

1. Je sens que je vais très bien m’adapter à la transition dans un système de soins pour adultes.

0	**1**	**2**	**3**	**4**
Pas vrai	Peu probable	Peut-être	Vrai	Très vrai



SDT

S'il te plaît, lis les paires d'énoncés, une paire à la fois, et pense à lequel des énoncés dans chaque paire semble le plus vrai pour toi à ce point dans ta vie. Indique à quel degré tu sens que l'énoncé A est vrai selon le degré auquel l'énoncé B est vrai, sur l'échelle à 5-points suivant chaque paire d'énoncés. Si tu sens que l'énoncé A est complètement vrai et que l'énoncé B est complètement faux, la réponse appropriée serait 1. Si les deux énoncés sont pareillement vrais, la réponse appropriée serait 3. Si tu sens que B seulement est vrai la réponse serait 5 et ainsi de suite.

1. A. Je sens que je choisis toujours les choses que je fais.

   B. Des fois, je sens que ce n'est pas réellement moi qui choisis les choses que je fais.

Seulement A me semble vrai	1	2	3	4	5	**Seulement B me semble vrai**

2. A. Mes émotions me sont parfois étrangères.

   B. Mes émotions semblent toujours m'appartenir.

Seulement A me semble vrai	1	2	3	4	5	**Seulement B me semble vrai**

3. A. Je choisis de faire ce que je dois faire.

   B. Je fais ce que je dois faire, mais je ne sens pas que c'est réellement mon choix.

Seulement A me semble vrai	1	2	3	4	5	**Seulement B me semble vrai**

4. A. Je sens que je suis rarement moi-même.

   B. Je sens que je suis toujours complètement moi-même.

Seulement A me semble vrai	1	2	3	4	5	**Seulement B me semble vrai**

5. A. Je fais ce que je fais parce que ça m'intéresse.

B. Je fais ce que je fais parce que je dois le faire.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

6. A. Quand j'accomplis quelque chose, je sens souvent que ce n'est pas vraiment moi qui l'ai fait.

B. Quand j'accomplis quelque chose, je sens toujours que c'est moi qui l'ai fait.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

7. A. Je suis libre de faire tout ce que je décide de faire.

B. Ce que je fais n'est souvent pas ce que je choisirais de faire.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

8. A. Je sens parfois que mon corps m'est étranger.

B. Je sens toujours que mon corps fait partie de moi.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

9. A. Je me sens assez libre de faire tout ce que je choisis.

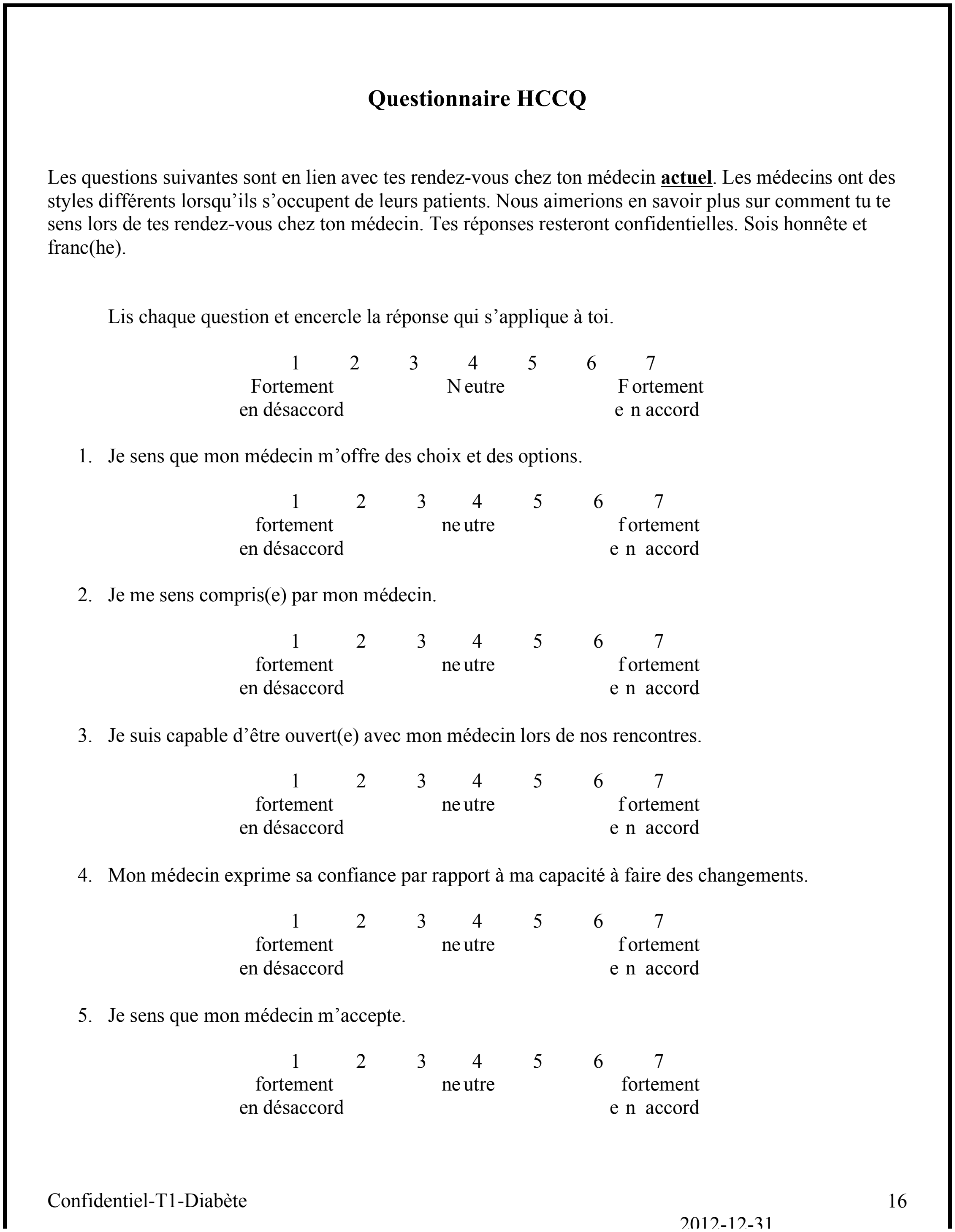
B. Je fais souvent des choses que je ne choisis pas de faire.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**

10. A. Parfois je regarde dans le miroir et je vois un étranger.

B. Quand je regarde dans le miroir c'est moi-même que je vois.

Seulement A 1 2 3 4 5 **Seulement B**
me semble vrai **me semble vrai**



Questionnaire HCCQ

Les questions suivantes sont en lien avec tes rendez-vous chez ton médecin **actuel**. Les médecins ont des styles différents lorsqu'ils s'occupent de leurs patients. Nous aimerions en savoir plus sur comment tu te sens lors de tes rendez-vous chez ton médecin. Tes réponses resteront confidentielles. Sois honnête et franc(he).

Lis chaque question et encercle la réponse qui s'applique à toi.

1	2	3	4	5	6	7
Fortement en désaccord			Neutre			Fortement en accord

1. Je sens que mon médecin m'offre des choix et des options.

1	2	3	4	5	6	7
fortement en désaccord			neutre			fortement en accord

2. Je me sens compris(e) par mon médecin.

1	2	3	4	5	6	7
fortement en désaccord			neutre			fortement en accord

3. Je suis capable d'être ouvert(e) avec mon médecin lors de nos rencontres.

1	2	3	4	5	6	7
fortement en désaccord			neutre			fortement en accord

4. Mon médecin exprime sa confiance par rapport à ma capacité à faire des changements.

1	2	3	4	5	6	7
fortement en désaccord			neutre			fortement en accord

5. Je sens que mon médecin m'accepte.

1	2	3	4	5	6	7
fortement en désaccord			neutre			fortement en accord

6. Mon médecin s’assure que je comprenne bien ma condition et ce que je dois faire.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

7. Mon médecin m’encourage à poser des questions.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

8. Je ressens beaucoup de confiance envers mon médecin.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

9. Mon médecin répond complètement et soigneusement à mes questions.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

10. Mon médecin écoute comment j’aimerais faire les choses.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

11. Mon médecin gère très bien les émotions des gens.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

12. Je sens que mon médecin se soucie de moi en tant que personne.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

13. Je ne me sens pas très bien par rapport à la façon dont me parle mon médecin.

1	2	3	4	5	6	7
fortement en désaccord			neutre			fortement en accord

14. Mon médecin essaie de comprendre comment je vois les choses avant de suggérer une nouvelle façon de les faire.

1	2	3	4	5	6	7
fortement en désaccord			neutre			fortement en accord

15. Je me sens capable de partager mes émotions avec mon médecin.

1	2	3	4	5	6	7
fortement en désaccord			neutre			fortement en accord

Questionnaire TSRQ

Il existe de nombreuses raisons pour lesquelles les patients prennent leurs médicaments, vérifient leur glucose, suivent leur diète ou font de l'exercice régulièrement. Nous te demandons de penser aux comportements suivants et d'indiquer à quel point ils sont vrais pour toi en encerclant la bonne réponse.

Voici l'échelle :

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

A. Je prends mes médicaments pour le diabète et/ou je vérifie mon glucose parce que :

1. D'autres personnes seraient fâchées contre moi si je ne le faisais pas.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

2. Je trouve que c'est un défi personnel de le faire.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

3. Je crois vraiment que le fait de contrôler mon diabète va améliorer ma santé.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

4. Je me sentirais coupable si je ne faisais pas ce que mon médecin me dit.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

5. Je veux que mon médecin pense que je suis un(e) bon(ne) patient(e).

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

6. Je me sentirais mal par rapport à moi-même si je ne le faisais pas.

1 2 3 4 5 6 7
Pas vrai du tout Assez vrai Très vrai

7. C’est excitant d’essayer de garder mon glucose à un niveau sain.

1 2 3 4 5 6 7
Pas vrai du tout Assez vrai Très vrai

8. Je ne veux pas que d’autres personnes soient déçues de moi.

1 2 3 4 5 6 7
Pas vrai du tout Assez vrai Très vrai

B. La raison pour laquelle je suis ma diète et que je fais de l’exercice régulièrement est parce que :

9. D’autres personnes seraient fâchées contre moi si je ne le faisais pas.

1 2 3 4 5 6 7
Pas vrai du tout Assez vrai Très vrai

10. Je crois vraiment que faire ces choses est important pour rester en santé.

1 2 3 4 5 6 7
Pas vrai du tout Assez vrai Très vrai

11. J’aurais honte de moi si je ne le faisais pas.

1 2 3 4 5 6 7
Pas vrai du tout Assez vrai Très vrai

12. Il est plus facile de faire ce qu’on me dit que d’y penser.

1 2 3 4 5 6 7
Pas vrai du tout Assez vrai Très vrai

13. J’ai bien réfléchi à ma diète et à l’exercice et je crois que c’est la bonne chose à faire.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

14. Je veux que les autres voient que je suis capable de suivre ma diète et de rester en forme.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

15. Je le fais seulement parce que mon médecin me l’a dit.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

16. Personnellement, je sens que suivre ma diète et faire de l’exercice sont les meilleures choses pour moi.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

17. Je me sentirais coupable si je ne surveillais pas ma diète et si je ne faisais pas d’exercice.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

18. Faire de l’exercice régulièrement et suivre ma diète sont des choix que je veux vraiment faire.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

19. C’est un défi d’apprendre comment vivre avec le diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

Questionnaire PCS

Réponds à chaque question qui suit en indiquant à quel point elles sont vraies pour toi par rapport à ton expérience de la maladie.

Utilise l'échelle suivante :

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

1. Je me sens confiant(e) quant à ma capacité de gérer mon diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

2. Présentement, je suis capable de gérer mon diabète.

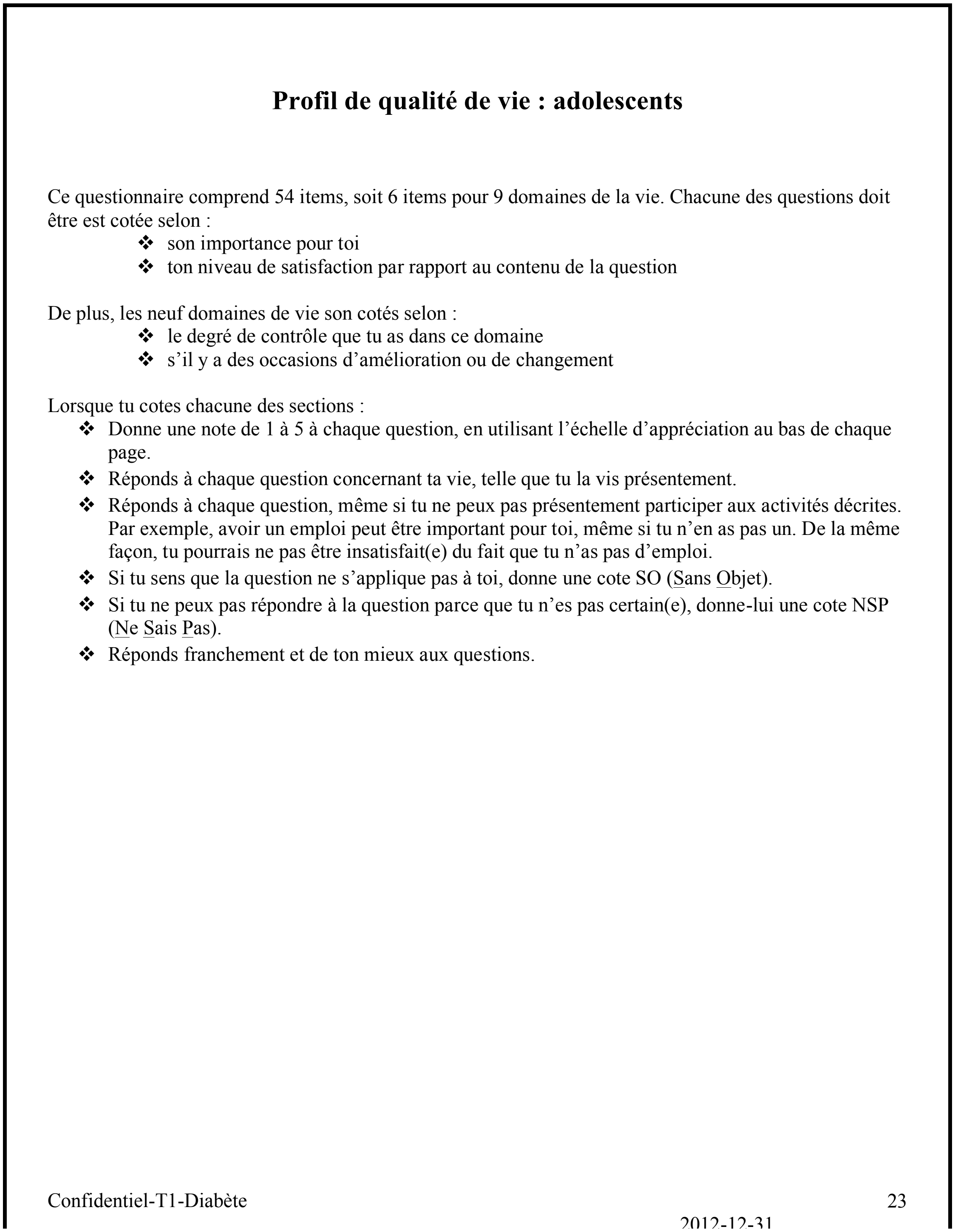
1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

3. Présentement, je suis capable de suivre ma propre routine de soins associée au diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

4. Je me sens capable de relever le défi de contrôler mon diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai



Profil de qualité de vie : adolescents

Ce questionnaire comprend 54 items, soit 6 items pour 9 domaines de la vie. Chacune des questions doit être est cotée selon :

- son importance pour toi
- ton niveau de satisfaction par rapport au contenu de la question

De plus, les neuf domaines de vie son cotés selon :

- le degré de contrôle que tu as dans ce domaine
- s'il y a des occasions d'amélioration ou de changement

Lorsque tu cotes chacune des sections :

- Donne une note de 1 à 5 à chaque question, en utilisant l'échelle d'appréciation au bas de chaque page.
- Réponds à chaque question concernant ta vie, telle que tu la vis présentement.
- Réponds à chaque question, même si tu ne peux pas présentement participer aux activités décrites. Par exemple, avoir un emploi peut être important pour toi, même si tu n'en as pas un. De la même façon, tu pourrais ne pas être insatisfait(e) du fait que tu n'as pas d'emploi.
- Si tu sens que la question ne s'applique pas à toi, donne une cote SO (Sans Objet).
- Si tu ne peux pas répondre à la question parce que tu n'es pas certain(e), donne-lui une cote NSP (Ne Sais Pas).
- Réponds franchement et de ton mieux aux questions.

ÊTRE **IMPORTANCE**

PHYSIQUE : Mon corps et ma santé

Quelle est l'importance que j'accorde à

1. être responsable par rapport au sexe. ______
2. faire des choix sains (alcool, drogues, fumer). ______
3. mon apparence - ce que j'ai l'air. ______
4. mon conditionnement physique (exercice) et être en forme. ______
5. ma santé physique. ______
6. mon alimentation et la nourriture que je mange. ______

PSYCHOLOGIQUE : Mes pensées, mes sentiments

Quelle est l'importance que j'accorde à

7. être sans inquiétude et sans stress. ______
8. la façon dont je me sens par rapport à moi-même. ______
9. me connaître. ______
10. savoir où je vais. ______
11. penser et à agir de façon autonome. ______
12. faire confiance aux autres. ______

SPIRITUEL : Mes croyances et mes valeurs

Quelle est l'importance que j'accorde à

13. faire partie des choses autour de moi ______
14. sentir que la vie a un sens. ______
15. avoir confiance en l'avenir. ______
16. avoir des croyances religieuses ou spirituelles. ______
17. aider les autres. ______
18. mes propres idées de ce qui est bien ou de ce qui est mal. ______

ÉCHELLE D'APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			Sans objet : SO	

APPARTENIR **IMPORTANCE**

PHYSIQUE : Où je vis et passe mon temps

Quelle est l’importance que j’accorde à

19. me sentir en sécurité quand je sors (école, voisinage). ______
20. au coin du pays dans lequel je vis. ______
21. la terre et à son environnement. ______
22. la maison ou à l’appartement où je vis. ______
23. au voisinage dans lequel je vis. ______
24. l’école que je fréquente. ______

SOCIAL : Les personnes autour de moi

Quelle est l’importance que j’accorde à

25. agir de façon responsable envers les autres. ______
26. être apprécié(e) des autres. ______
27. m’entendre avec ma famille. ______
28. avoir une copine ou un copain (blonde / chum). ______
29. faire des fêtes et avoir des choses à faire. ______
30. aux amis(es) que j’ai. ______

COMMUNAUTÉ : Mon accès aux choses

Quelle est l’importance que j’accorde à

31. être capable d’aller chercher des services médicaux et sociaux tout(e) seul(e). ______
32. recevoir une bonne éducation. ______
33. avoir assez d’argent. ______
34. avoir des emplois disponibles pendant que je fréquente encore l’école. ______
35. avoir des endroits où aller avec mes amis. ______
36. avoir des choses à faire dans ma communauté dans mon temps libre. ______

ÉCHELLE D’APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			Sans objet : SO	

DEVENIR **IMPORTANCE**

PRATIQUE : Les choses quotidiennes que je fais

Quelle est l’importance que j’accorde à

37. faire du travail bénévole pour les autres. ______
38. prendre soin de mon apparence et de mon hygiène. ______
39. étudier et à faire mes devoirs. ______
40. aux tâches que je fais à la maison. ______
41. aux choses que je fais à l’école. ______
42. au travail que je fais dans mon emploi, pendant que je fréquente encore l’école. ______

LOISIRS : Les choses que je fais pour le plaisir

Quelle est l’importance que j’accorde à

43. assister à des activités de divertissement publiques. ______
44. avoir des passe-temps et des intérêts personnels. ______
45. des activités intérieures (ex. lecture, télévision, etc.). ______
46. des activités à l’intérieur (ex. marche, bicyclette, etc.). ______
47. participer à des sports et à des activités récréatives. ______
48. visiter et à passer du temps avec les autres. ______

DÉVELOPPEMENT : Les choses que je fais pour m’améliorer et changer.

Quelle est l’importance que j’accorde à

49. réussir dans les choses que je fais. ______
50. m’entendre mieux avec les autres. ______
51. apprendre de nouvelles choses. ______
52. planifier en vue d’un emploi ou d’une carrière. ______
53. planifier en vue d’une éducation ou d’une formation. ______
54. résoudre mes problèmes. ______

ÉCHELLE D’APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			Sans objet : SO	

ÊTRE **SATISFACTION**

PHYSIQUE : Mon corps et ma santé

À quel point je suis satisfait(e) de

1. être responsable par rapport au sexe. ______
2. faire des choix sains (alcool, drogues, fumer). ______
3. mon apparence – ce que j'ai l'air. ______
4. mon conditionnement physique (exercice) et être en forme. ______
5. ma santé physique. ______
6. mon alimentation et la nourriture que je mange. ______

PSYCHOLOGIQUE : Mes pensées, mes sentiments

À quel point je suis satisfait(e) de

7. être sans inquiétude et sans stress. ______
8. la façon dont je me sens par rapport à moi-même. ______
9. me connaître. ______
10. savoir où je vais. ______
11. penser et à agir de façon autonome. ______
12. faire confiance aux autres. ______

SPIRITUEL : Mes croyances et mes valeurs

À quel point je suis satisfait(e) de

13. faire partie des choses autour de moi ______
14. sentir que la vie a un sens. ______
15. avoir confiance en l'avenir. ______
16. avoir des croyances religieuses ou spirituelles. ______
17. aider les autres. ______
18. mes propres idées de ce qui est bien ou de ce qui est mal. ______

ÉCHELLE D'APPRÉCIATION : SATISFACTION				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			Sans objet : SO	

APPARTENIR **SATISFACTION**

PHYSIQUE : Où je vis et passe mon temps

À quel point je suis satisfait(e) de

19. me sentir en sécurité quand je sors (école, voisinage). ______
20. au coin du pays dans lequel je vis. ______
21. la terre et à son environnement. ______
22. la maison ou à l'appartement où je vis. ______
23. au voisinage dans lequel je vis. ______
24. l'école que je fréquente. ______

SOCIAL : Les personnes autour de moi

À quel point je suis satisfait(e) de

25. agir de façon responsable envers les autres. ______
26. être apprécié(e) des autres. ______
27. m'entendre avec ma famille. ______
28. avoir une copine ou un copain (blonde/chum). ______
29. faire des fêtes et avoir des choses à faire. ______
30. aux amis(es) que j'ai. ______

COMMUNAUTÉ : Mon accès aux choses

À quel point je suis satisfait(e) de

31. être capable d'aller chercher des services médicaux et sociaux tout(e) seul(e). ______
32. recevoir une bonne éducation. ______
33. avoir assez d'argent. ______
34. avoir des emplois disponibles pendant que je fréquente encore l'école. ______
35. avoir des endroits où aller avec mes amis. ______
36. avoir des choses à faire dans ma communauté dans mon temps libre. ______

ÉCHELLE D'APPRÉCIATION : SATISFACTION				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			Sans objet : SO	

DEVENIR **SATISFACTION**

PRATIQUE : Les choses quotidiennes que je fais

À quel point je suis satisfait(e) de

37. faire du travail bénévole pour les autres. ______
38. prendre soin de mon apparence et de mon hygiène. ______
39. étudier et à faire mes devoirs. ______
40. aux tâches que je fais à la maison. ______
41. aux choses que je fais à l'école. ______
42. au travail que je fais dans mon emploi, pendant que je fréquence encore l'école. ______

LOISIRS : Les choses que je fais pour le plaisir

À quel point je suis satisfait(e) de

43. assister à des activités de divertissement publiques. ______
44. avoir des passe-temps et des intérêts personnels. ______
45. des activités intérieures (ex. lecture, télévision, etc.). ______
46. des activités à l'intérieur (ex. marche, bicyclette, etc.). ______
47. participer à des sports et à des activités récréatives. ______
48. visiter et à passer du temps avec les autres. ______

DÉVELOPPEMENT : Les choses que je fais pour m'améliorer et changer.

À quel point je suis satisfait(e) de

49. réussir dans les choses que je fais. ______
50. m'entendre mieux avec les autres. ______
51. apprendre de nouvelles choses. ______
52. planifier en vue d'un emploi ou d'une carrière. ______
53. planifier en vue d'une éducation ou d'une formation. ______
54. résoudre mes problèmes. ______

ÉCHELLE D'APPRÉCIATION : SATISFACTION				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			Sans objet : SO	

CONTRÔLE

Combien de contrôle est-ce que j'ai sur

1. mon corps et ma santé physique. ______
2. mes pensées et mes émotions. ______
3. mes croyances et mes valeurs. ______
4. où je vis et où je passe mon temps. ______
5. les personnes autour de moi. ______
6. mon accès aux choses dans ma communauté. ______
7. les choses pratiques que je fais. ______
8. les choses que je fais pour le plaisir et l'amusement. ______
9. les choses que je fais pour me débrouiller et pour changer. ______

ÉCHELLE D'APPRÉCIATION : CONTRÔLE				
1 Aucun	2 Un peu	3 Un certain contrôle	4 Assez	5 Beaucoup
Ne sais pas : NSP			Sans objet : SO	

OCCASIONS

À quelle fréquence est-ce que j'ai l'occasion d'améliorer

1. mon corps et ma santé physique. ______
2. mes pensées et mes émotions. ______
3. mes croyances et mes valeurs. ______
4. là où je vis et où je passe mon temps. ______
5. les personnes autour de moi. ______
6. mon accès aux choses dans ma communauté. ______
7. les choses pratiques que je fais. ______
8. les choses que je fais pour le plaisir et l'amusement. ______
9. les choses que je fais pour me débrouiller et pour changer. ______

ÉCHELLE D'APPRÉCIATION : OCCASIONS				
1 Aucune	2 Peu	3 Quelques	4 Assez	5 Un grand nombre
Ne sais pas : NSP			Sans objet : SO	

Médicaments

A. Il arrive à tout le monde de ne pas prendre ses médicaments à un moment donné. Les énoncés qui suivent représentent des raisons communes pour lesquelles les personnes peuvent ne pas prendre leurs médicaments. À quelle fréquence ces raisons ont-elles fait en sorte que tu n'as pas pris tes médicaments? Indique un chiffre par énoncé en utilisant l'échelle suivante.

Très souvent	**Souvent**	**Parfois**	**Rarement**	**Jamais**
1	**2**	**3**	**4**	**5**

À quelle fréquence tu ne prends pas tes médicaments…

1. _____ quand tu n'es pas à la maison.
2. _____ quand tu te sens en santé.
3. _____ quand tu es occupé(e) avec autres choses.
4. _____ quand tu n'as plus de médicaments et que tu n'as pas renouvelé ta prescription.
5. _____ quand tu oublies tout simplement de prendre tes médicaments.
6. _____ quand tu n'as pas assez d'argent pour acheter les médicaments.
7. _____ quand tu déplaces ta bouteille de médicaments.
8. _____ quand d'autres personnes te disent que les médicaments ne sont pas bons.
9. _____ quand tu as trop de pilules à prendre.
10. _____ quand tu te sens mal après avoir pris les médicaments.
11. _____ quand tu en as simplement assez de prendre des pilules.

B. À quelle fréquence as-tu fait ce qui suit? Indique un chiffre pour chaque énoncé en utilisant l'échelle suivante.

Très souvent	**Souvent**	**Parfois**	**Rarement**	**Jamais**	**Ne fait pas partie de mon traitement**
1	**2**	**3**	**4**	**5**	**6**

1. _____ J'ai oublié de rapporter un problème particulier à mon médecin.
2. _____ Je n'ai pas pris de rendez-vous avec mon médecin ou à la clinique comme j'étais supposé(e).
3. _____ J'ai manqué des rendez-vous que j'avais pris avec mon médecin ou à ma clinique.
4. _____ J'ai oublié de téléphoner la clinique de diabète.

Renseignements démographiques

A.

1. Date d'aujourd'hui : ________________

2. Date de naissance : ________________

3. Âge : ________________

4. Sexe : M _____ F _____

5. Lequel des énoncés suivants représente le mieux ta situation actuelle?
   a. Je suis étudiant (e) à temps plein et je ne travaille pas.
   b. Je suis étudiant (e) à temps partiel et je ne travaille pas.
   c. Je suis étudiant (e) à temps plein et je travaille à temps partiel.
   d. Je suis étudiant (e) à temps partiel et je travaille à temps partiel.
   e. Je travaille à temps plein.
   f. Je travaille à temps partiel.
   g. Autre : ____

6. Niveau d'éducation actuel ou niveau d'éducation atteint : ________________

7. Origine ethnique : ________________

8. As-tu reçu un diagnostique médical? Non _____ Oui _____

Si oui, réponds aux questions suivantes :

I. Diagnostique : _______________________________________
(e.g. asthme, diabète, insuffisance rénale etc.)

II. Date du diagnostique (ou année seulement) : ________________

III. Quel âge avais-tu? ________________

IV. Quel traitement as-tu reçu? ________________

9. Présentement, prends-tu des médicaments? _______________

10. Si oui, quels médicaments prends-tu?

____ ___________________

____

____

____ _

____

11. Depuis quand reçois-tu des soins dans cet hôpital ou à cette clinique? _________

12. Ton médecin ou infirmière a-t-il (elle) discuté de la transition avec toi? Non ___ Oui ___

13. À quel âge penses-tu que la transition au milieu hospitalier adulte pour les adolescents comme toi devrait avoir lieu? ________

14. Comment te sens-tu par rapport à ta transition? Te sens-tu soutenu(e) par ton entourage (tes parents, le personnel médical)?

____

____

____

____

____ ____________________________

15. As-tu vécu des changements importants dans la dernière année? (Exemple : déménagement, changement d'école, décès, arrêt d'éducation, etc.)?

____

____

____ ________________________

____

B.

I. Présentement, habites-tu chez tes parents? Non ___ Oui ___

II. Tes parents sont-ils :

a. Mariés
b. Divorcés (si oui, depuis quand? ______)
c. Séparés (si oui, depuis quand? ______)
d. Autre

III. As-tu des frères et sœurs? Non ___ Oui ___

Si oui, combien? _______

IV. Quelle est :

a. L'occupation de ta mère? __________________

b. L'occupation de ton père? __________________

V. Quel est le plus haut niveau d'éducation de ta mère?

a. Secondaire
b. C.E.G.E.P
c. Université - Études supérieures
d. Je ne sais pas.

VI. Quel est le plus haut niveau d'éducation de ton père?

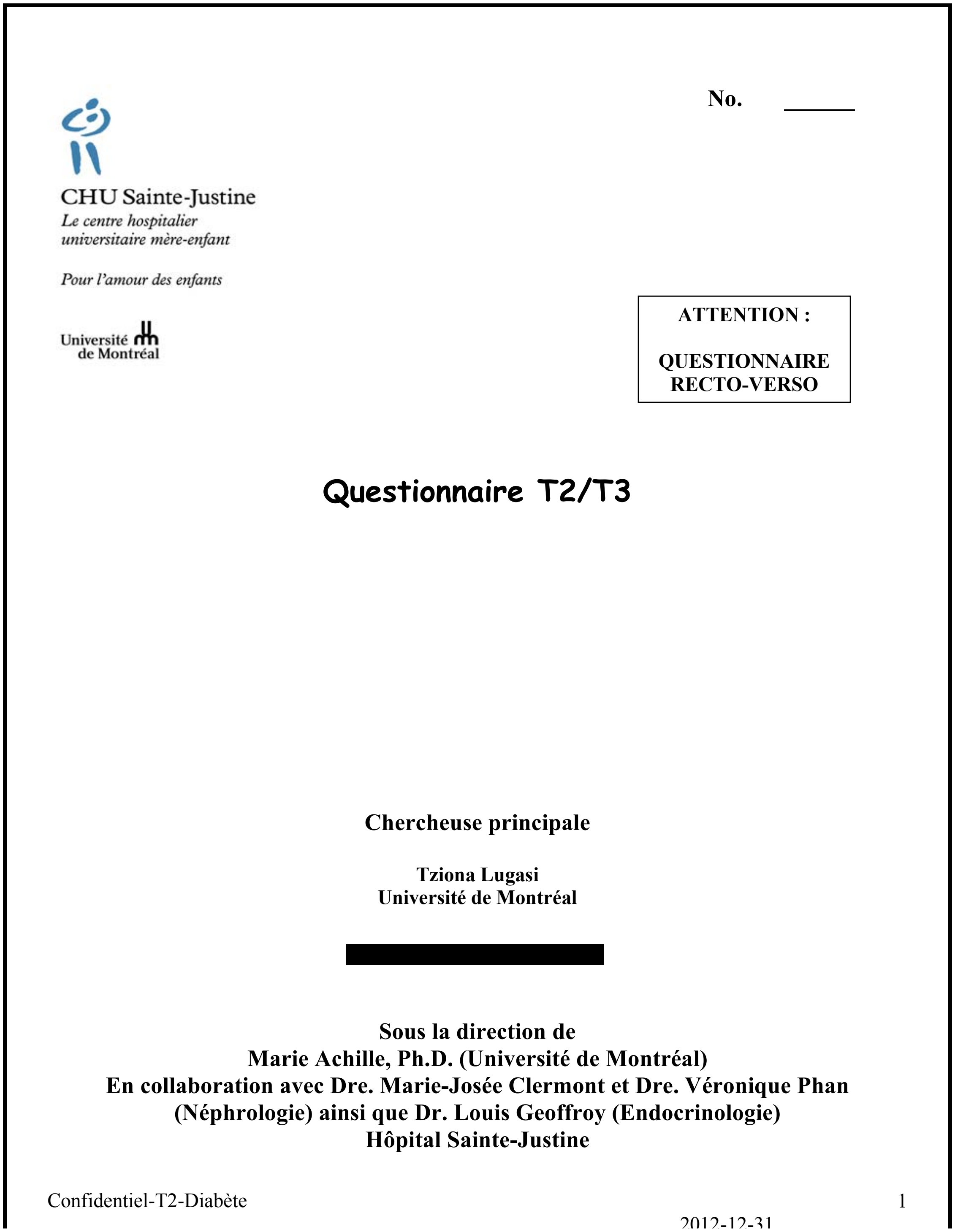
a. Secondaire
b. C.E.G.E.P
c. Université - Études supérieures
d. Je ne sais pas.

VII. Quel est le revenu annuel de ta famille?

a. Moins de 10 000 $
b. 10 000 - 19 999 $
c. 20 000 - 34 999 $
d. 35 000 - 49 999 $
e. 50 000 - 74 999 $
f. 75 000 - 99 999 $
g. Plus de 100 000 $
h. Je ne sais pas.

Annexe J

Questionnaire T2/T3- patients



CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

Université de Montréal

No. ______

ATTENTION :

QUESTIONNAIRE RECTO-VERSO

Questionnaire T2/T3

Chercheuse principale

Tziona Lugasi
Université de Montréal

[redacted]

Sous la direction de
Marie Achille, Ph.D. (Université de Montréal)
En collaboration avec Dre. Marie-Josée Clermont et Dre. Véronique Phan (Néphrologie) ainsi que Dr. Louis Geoffroy (Endocrinologie)
Hôpital Sainte-Justine

Cher patient, chère patiente,

Tout d'abord, je souhaite te remercier de prendre le temps de participer à cette étude. Ton temps ainsi que ton énergie sont grandement appréciés et nous espérons que les renseignements recueillis tout au long de cette étude serviront à faciliter la transition vers un centre pour adulte pour les futurs patients comme toi.

Ce questionnaire représente le deuxième de quatre questionnaires que nous te demanderons de remplir dans le cadre de cette étude. Il contient des questions concernant ton comportement psychologique et social, ta transition au milieu hospitalier adulte, tes sentiments de compétence, ta qualité de vie et tes médicaments.

La plupart des questions sont à choix multiples et nous te demandons d'encercler la réponse qui te décrit le mieux. Il n'existe pas de bonne ou de mauvaise réponse aux questions, nous nous intéressons uniquement à ton vécu.

Si tu as des questions, n'hésite pas à me les poser. Il me fera plaisir de t'aider. Tu peux me contacter au numéro ou à l'adresse courriel indiqués au bas de la page.

Je te remercie de ta participation!

Cordialement,

Tziona Lugasi

[redacted]

[redacted]

SDT

S'il te plaît, lis les paires d'énoncés, une paire à la fois, et pense à lequel des énoncés dans chaque paire semble le plus vrai pour toi à ce point dans ta vie. Indique à quel degré tu sens que l'énoncé A est vrai selon le degré auquel l'énoncé B est vrai, sur l'échelle à 5-points suivant chaque paire d'énoncés. Si tu sens que l'énoncé A est complètement vrai et que l'énoncé B est complètement faux, la réponse appropriée serait 1. Si les deux énoncés sont pareillement vrais, la réponse appropriée serait 3. Si tu sens que B seulement est vrai la réponse serait 5 et ainsi de suite.

1. A. Je sens que je choisis toujours les choses que je fais.

   B. Des fois, je sens que ce n'est pas réellement moi qui choisis les choses que je fais.

Seulement A me semble vrai	1	2	3	4	5	**Seulement B me semble vrai**

2. A. Mes émotions me sont parfois étrangères.

   B. Mes émotions semblent toujours m'appartenir.

Seulement A me semble vrai	1	2	3	4	5	**Seulement B me semble vrai**

3. A. Je choisis de faire ce que je dois faire.

   B. Je fais ce que je dois faire, mais je ne sens pas que c'est réellement mon choix.

Seulement A me semble vrai	1	2	3	4	5	**Seulement B me semble vrai**

4. A. Je sens que je suis rarement moi-même.

   B. Je sens que je suis toujours complètement moi-même.

Seulement A me semble vrai	1	2	3	4	5	**Seulement B me semble vrai**

5. A. Je fais ce que je fais parce que ça m’intéresse.

B. Je fais ce que je fais parce que je dois le faire.

Seulement A **me semble vrai**	1	2	3	4	5	**Seulement B** **me semble vrai**

6. A. Quand j’accomplis quelque chose, je sens souvent que ce n’est pas vraiment moi qui l’ai fait.

B. Quand j’accomplis quelque chose, je sens toujours que c’est moi qui l’ai fait.

Seulement A **me semble vrai**	1	2	3	4	5	**Seulement B** **me semble vrai**

7. A. Je suis libre de faire tout ce que je décide de faire.

B. Ce que je fais n’est souvent pas ce que je choisirais de faire.

Seulement A **me semble vrai**	1	2	3	4	5	**Seulement B** **me semble vrai**

8. A. Je sens parfois que mon corps m’est étranger.

B. Je sens toujours que mon corps fait partie de moi.

Seulement A **me semble vrai**	1	2	3	4	5	**Seulement B** **me semble vrai**

9. A. Je me sens assez libre de faire tout ce que je choisis.

B. Je fais souvent des choses que je ne choisis pas de faire.

Seulement A **me semble vrai**	1	2	3	4	5	**Seulement B** **me semble vrai**

10. A. Parfois je regarde dans le miroir et je vois un étranger.

B. Quand je regarde dans le miroir c’est moi-même que je vois.

Seulement A **me semble vrai**	1	2	3	4	5	**Seulement B** **me semble vrai**

Questionnaire HCCQ

Les questions suivantes sont en lien avec tes rendez-vous chez ton médecin **actuel** (à la clinique où tu as été transféré(e)). Les médecins ont des styles différents lorsqu'ils s'occupent de leurs patients. Nous aimerions en savoir plus sur comment tu te sens lors de tes rendez-vous chez ton médecin. Tes réponses resteront confidentielles. Sois honnête et franc(he).

Lis chaque question et encercle la réponse qui s'applique à toi.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

1. Je sens que mon médecin actuel m'offre des choix et des options.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

2. Je me sens compris(e) par mon médecin actuel.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

3. Je suis capable d'être ouvert(e) avec mon médecin actuel lors de nos rencontres.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

4. Mon médecin actuel exprime sa confiance par rapport à ma capacité à faire des changements.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

5. Je sens que mon médecin actuel m'accepte.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

6. Mon médecin actuel s’assure que je comprenne bien ma condition et ce que je dois faire.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

7. Mon médecin actuel m’encourage à poser des questions.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

8. Je ressens beaucoup de confiance envers mon médecin actuel.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

9. Mon médecin actuel répond complètement et soigneusement à mes questions.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

10. Mon médecin actuel écoute comment j’aimerais faire les choses.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

11. Mon médecin gère très bien les émotions des gens.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

12. Je sens que mon médecin actuel se soucie de moi en tant que personne.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

13. Je ne me sens pas très bien par rapport à la façon dont me parle mon médecin actuel.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

14. Mon médecin actuel essaie de comprendre comment je vois les choses avant de suggérer une nouvelle façon de les faire.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

15. Je me sens capable de partager mes émotions avec mon médecin actuel.

1 2 3 4 5 6 7
fortement neutre fortement
en désaccord en accord

Questionnaire TSRQ

Il existe de nombreuses raisons pour lesquelles les patients prennent leurs médicaments, vérifient leur glucose, suivent leur diète ou font de l'exercice régulièrement. Nous te demandons de penser aux comportements suivants et d'indiquer à quel point ils sont vrais pour toi en encerclant la bonne réponse.

Voici l'échelle :

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

A. Je prends mes médicaments pour le diabète et/ou je vérifie mon glucose parce que :

1. D'autres personnes seraient fâchées contre moi si je ne le faisais pas.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

2. Je trouve que c'est un défi personnel de le faire.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

3. Je crois vraiment que le fait de contrôler mon diabète va améliorer ma santé.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

4. Je me sentirais coupable si je ne faisais pas ce que mon médecin me dit.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

5. Je veux que mon médecin pense que je suis un(e) bon(ne) patient(e).

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

6. Je me sentirais mal par rapport à moi-même si je ne le faisais pas.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

7. C'est excitant d'essayer de garder mon glucose à un niveau sain.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

8. Je ne veux pas que d'autres personnes soient déçues de moi.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

B. La raison pour laquelle je suis ma diète et que je fais de l'exercice régulièrement est parce que :

9. D'autres personnes seraient fâchées contre moi si je ne le faisais pas.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

10. Je crois vraiment que faire ces choses est important pour rester en santé.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

11. J'aurais honte de moi si je ne le faisais pas.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

12. Il est plus facile de faire ce qu'on me dit que d'y penser.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

13. J’ai bien réfléchi à ma diète et à l’exercice et je crois que c’est la bonne chose à faire.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

14. Je veux que les autres voient que je suis capable de suivre ma diète et de rester en forme.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

15. Je le fais seulement parce que mon médecin me l’a dit.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

16. Personnellement, je sens que suivre ma diète et faire de l’exercice sont les meilleures choses pour moi.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

17. Je me sentirais coupable si je ne surveillais pas ma diète et si je ne faisais pas d’exercice.

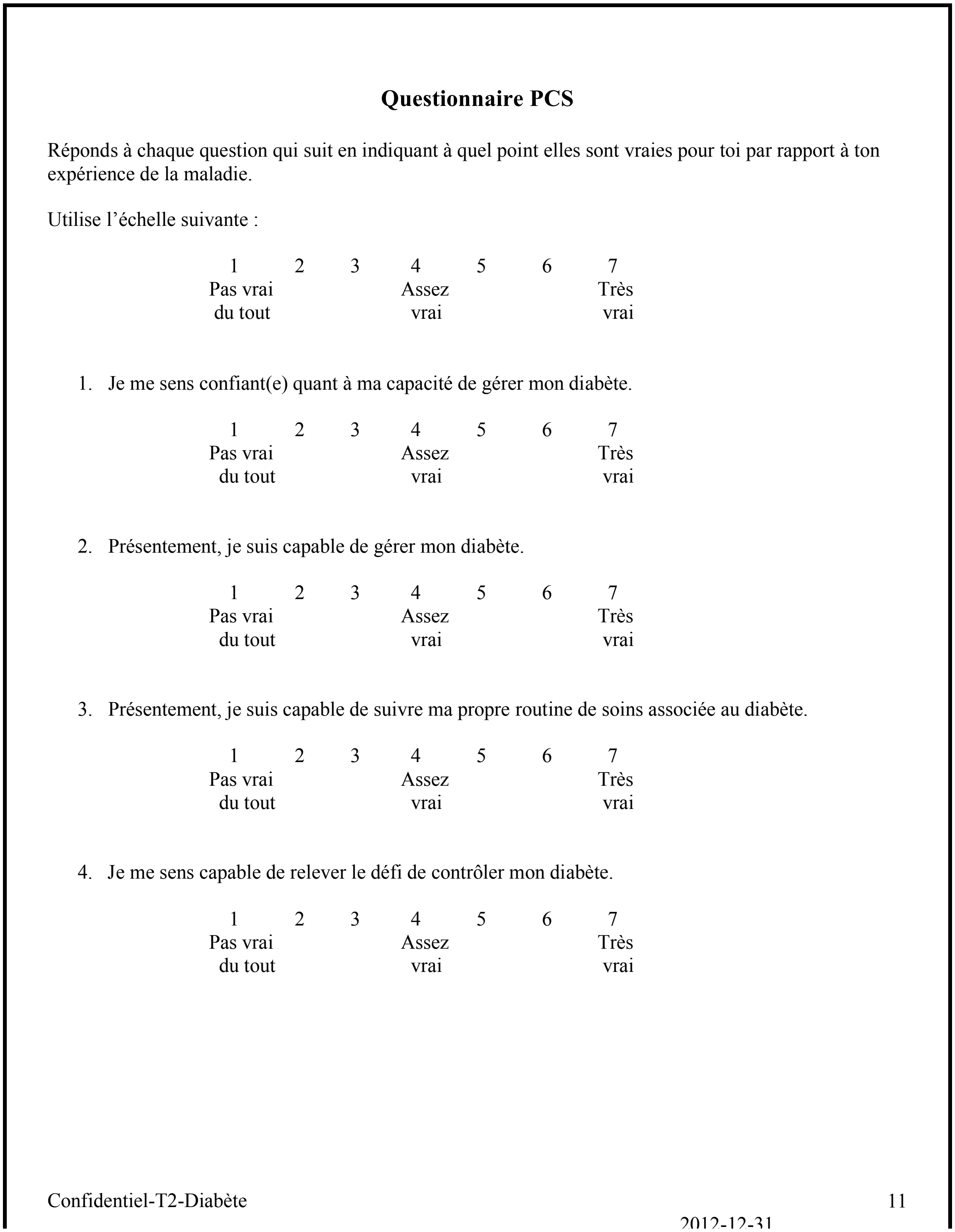
1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

18. Faire de l’exercice régulièrement et suivre ma diète sont des choix que je veux vraiment faire.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

19. C’est un défi d’apprendre comment vivre avec le diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai



Questionnaire PCS

Réponds à chaque question qui suit en indiquant à quel point elles sont vraies pour toi par rapport à ton expérience de la maladie.

Utilise l'échelle suivante :

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

1. Je me sens confiant(e) quant à ma capacité de gérer mon diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

2. Présentement, je suis capable de gérer mon diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

3. Présentement, je suis capable de suivre ma propre routine de soins associée au diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

4. Je me sens capable de relever le défi de contrôler mon diabète.

1	2	3	4	5	6	7
Pas vrai du tout			Assez vrai			Très vrai

Confidentiel-T2-Diabète 11
2012-12-31

Profil de qualité de vie : adolescents

Ce questionnaire comprend 54 items, soit 6 items pour 9 domaines de la vie. Chacune des questions doit être est cotée selon :

- son importance pour toi
- ton niveau de satisfaction par rapport au contenu de la question

De plus, les neuf domaines de vie son cotés selon :

- le degré de contrôle que tu as dans ce domaine
- s'il y a des occasions d'amélioration ou de changement

Lorsque tu cotes chacune des sections :

- Donne une note de 1 à 5 à chaque question, en utilisant l'échelle d'appréciation au bas de chaque page.
- Réponds à chaque question concernant ta vie, telle que tu la vis présentement.
- Réponds à chaque question, même si tu ne peux pas présentement participer aux activités décrites. Par exemple, avoir un emploi peut être important pour toi, même si tu n'en as pas un. De la même façon, tu pourrais ne pas être insatisfait(e) du fait que tu n'as pas d'emploi.
- Si tu sens que la question ne s'applique pas à toi, donne une cote SO (Sans Objet).
- Si tu ne peux pas répondre à la question parce que tu n'es pas certain(e), donne-lui une cote NSP (Ne Sais Pas).
- Réponds franchement et de ton mieux aux questions.

ÊTRE **IMPORTANCE**

PHYSIQUE : Mon corps et ma santé

Quelle est l'importance que j'accorde à

1. être responsable par rapport au sexe. ______
2. faire des choix sains (alcool, drogues, fumer). ______
3. mon apparence - ce que j'ai l'air. ______
4. mon conditionnement physique (exercice) et être en forme. ______
5. ma santé physique. ______
6. mon alimentation et la nourriture que je mange. ______

PSYCHOLOGIQUE : Mes pensées, mes sentiments

Quelle est l'importance que j'accorde à

7. être sans inquiétude et sans stress. ______
8. la façon dont je me sens par rapport à moi-même. ______
9. me connaître. ______
10. savoir où je vais. ______
11. penser et à agir de façon autonome. ______
12. faire confiance aux autres. ______

SPIRITUEL : Mes croyances et mes valeurs

Quelle est l'importance que j'accorde à

13. faire partie des choses autour de moi ______
14. sentir que la vie a un sens. ______
15. avoir confiance en l'avenir. ______
16. avoir des croyances religieuses ou spirituelles. ______
17. aider les autres. ______
18. mes propres idées de ce qui est bien ou de ce qui est mal. ______

ÉCHELLE D'APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			Sans objet : SO	

APPARTENIR **IMPORTANCE**

PHYSIQUE : Où je vis et passe mon temps

Quelle est l’importance que j’accorde à

19. me sentir en sécurité quand je sors (école, voisinage). ______
20. au coin du pays dans lequel je vis. ______
21. la terre et à son environnement. ______
22. la maison ou à l’appartement où je vis. ______
23. au voisinage dans lequel je vis. ______
24. l’école que je fréquente. ______

SOCIAL : Les personnes autour de moi

Quelle est l’importance que j’accorde à

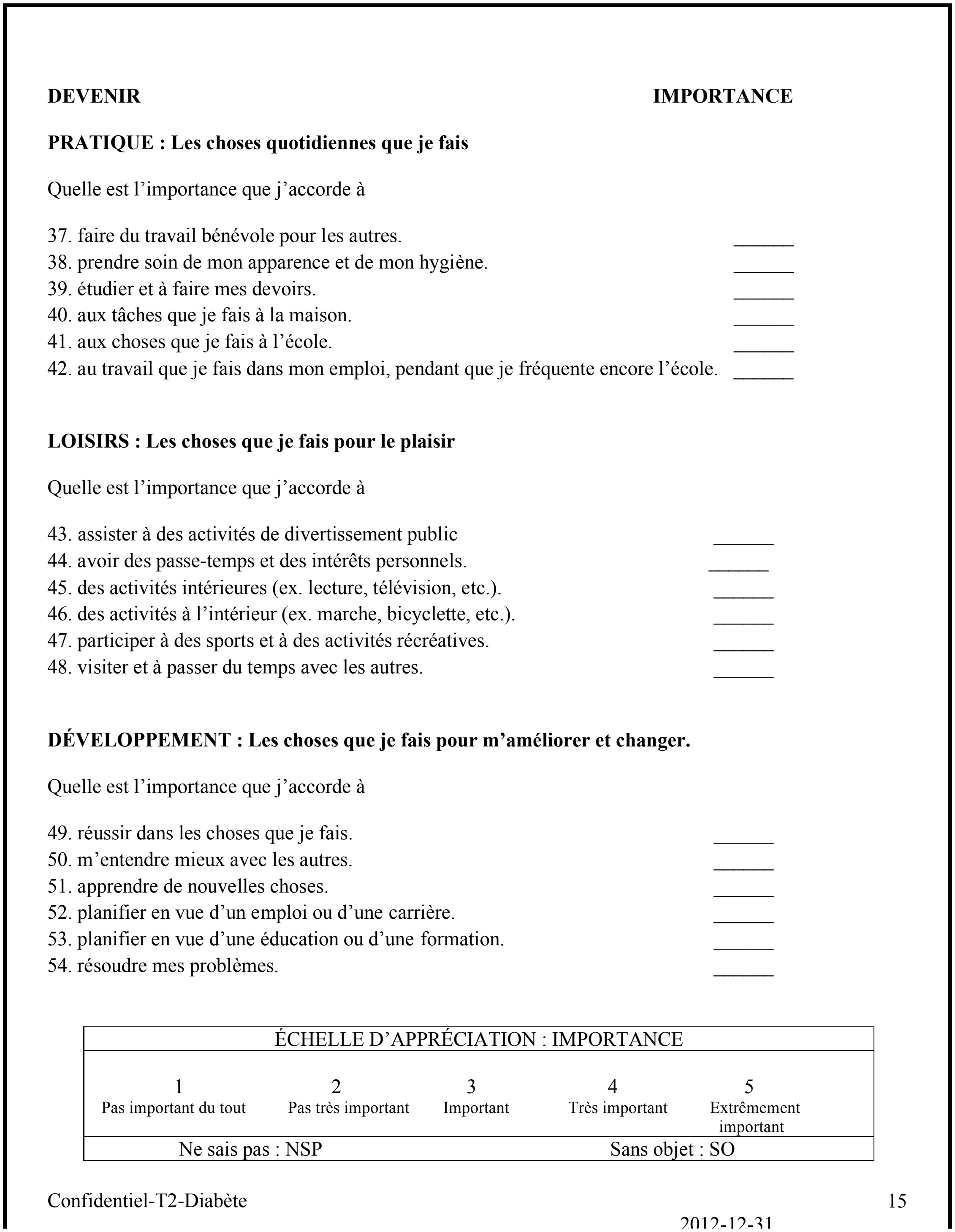
25. agir de façon responsable envers les autres. ______
26. être apprécié(e) des autres. ______
27. m’entendre avec ma famille. ______
28. avoir une copine ou un copain (blonde / chum). ______
29. faire des fêtes et avoir des choses à faire. ______
30. aux amis(es) que j’ai. ______

COMMUNAUTÉ : Mon accès aux choses

Quelle est l’importance que j’accorde à

31. être capable d’aller chercher des services médicaux et sociaux tout(e) seul(e). ______
32. recevoir une bonne éducation. ______
33. avoir assez d’argent. ______
34. avoir des emplois disponibles pendant que je fréquente encore l’école. ______
35. avoir des endroits où aller avec mes amis. ______
36. avoir des choses à faire dans ma communauté dans mon temps libre. ______

ÉCHELLE D’APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			Sans objet : SO	



DEVENIR **IMPORTANCE**

PRATIQUE : Les choses quotidiennes que je fais

Quelle est l’importance que j’accorde à

37. faire du travail bénévole pour les autres. ______
38. prendre soin de mon apparence et de mon hygiène. ______
39. étudier et à faire mes devoirs. ______
40. aux tâches que je fais à la maison. ______
41. aux choses que je fais à l’école. ______
42. au travail que je fais dans mon emploi, pendant que je fréquente encore l’école. ______

LOISIRS : Les choses que je fais pour le plaisir

Quelle est l’importance que j’accorde à

43. assister à des activités de divertissement public ______
44. avoir des passe-temps et des intérêts personnels. ______
45. des activités intérieures (ex. lecture, télévision, etc.). ______
46. des activités à l’intérieur (ex. marche, bicyclette, etc.). ______
47. participer à des sports et à des activités récréatives. ______
48. visiter et à passer du temps avec les autres. ______

DÉVELOPPEMENT : Les choses que je fais pour m’améliorer et changer.

Quelle est l’importance que j’accorde à

49. réussir dans les choses que je fais. ______
50. m’entendre mieux avec les autres. ______
51. apprendre de nouvelles choses. ______
52. planifier en vue d’un emploi ou d’une carrière. ______
53. planifier en vue d’une éducation ou d’une formation. ______
54. résoudre mes problèmes. ______

ÉCHELLE D’APPRÉCIATION : IMPORTANCE				
1 Pas important du tout	2 Pas très important	3 Important	4 Très important	5 Extrêmement important
Ne sais pas : NSP			Sans objet : SO	

ÊTRE **SATISFACTION**

PHYSIQUE : Mon corps et ma santé

À quel point je suis satisfait(e) de

1. être responsable par rapport au sexe. ______
2. faire des choix sains (alcool, drogues, fumer). ______
3. mon apparence – ce que j'ai l'air. ______
4. mon conditionnement physique (exercice) et être en forme. ______
5. ma santé physique. ______
6. mon alimentation et la nourriture que je mange. ______

PSYCHOLOGIQUE : Mes pensées, mes sentiments

À quel point je suis satisfait(e) de

7. être sans inquiétude et sans stress. ______
8. la façon dont je me sens par rapport à moi-même. ______
9. me connaître. ______
10. savoir où je vais. ______
11. penser et à agir de façon autonome. ______
12. faire confiance aux autres. ______

SPIRITUEL : Mes croyances et mes valeurs

À quel point je suis satisfait(e) de

13. faire partie des choses autour de moi ______
14. sentir que la vie a un sens. ______
15. avoir confiance en l'avenir. ______
16. avoir des croyances religieuses ou spirituelles. ______
17. aider les autres. ______
18. mes propres idées de ce qui est bien ou de ce qui est mal. ______

ÉCHELLE D'APPRÉCIATION : SATISFACTION				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			Sans objet : SO	

APPARTENIR **SATISFACTION**

PHYSIQUE : Où je vis et passe mon temps

À quel point je suis satisfait(e) de

19. me sentir en sécurité quand je sors (école, voisinage). ______
20. au coin du pays dans lequel je vis. ______
21. la terre et à son environnement. ______
22. la maison ou à l'appartement où je vis. ______
23. au voisinage dans lequel je vis. ______
24. l'école que je fréquente. ______

SOCIAL : Les personnes autour de moi

À quel point je suis satisfait(e) de

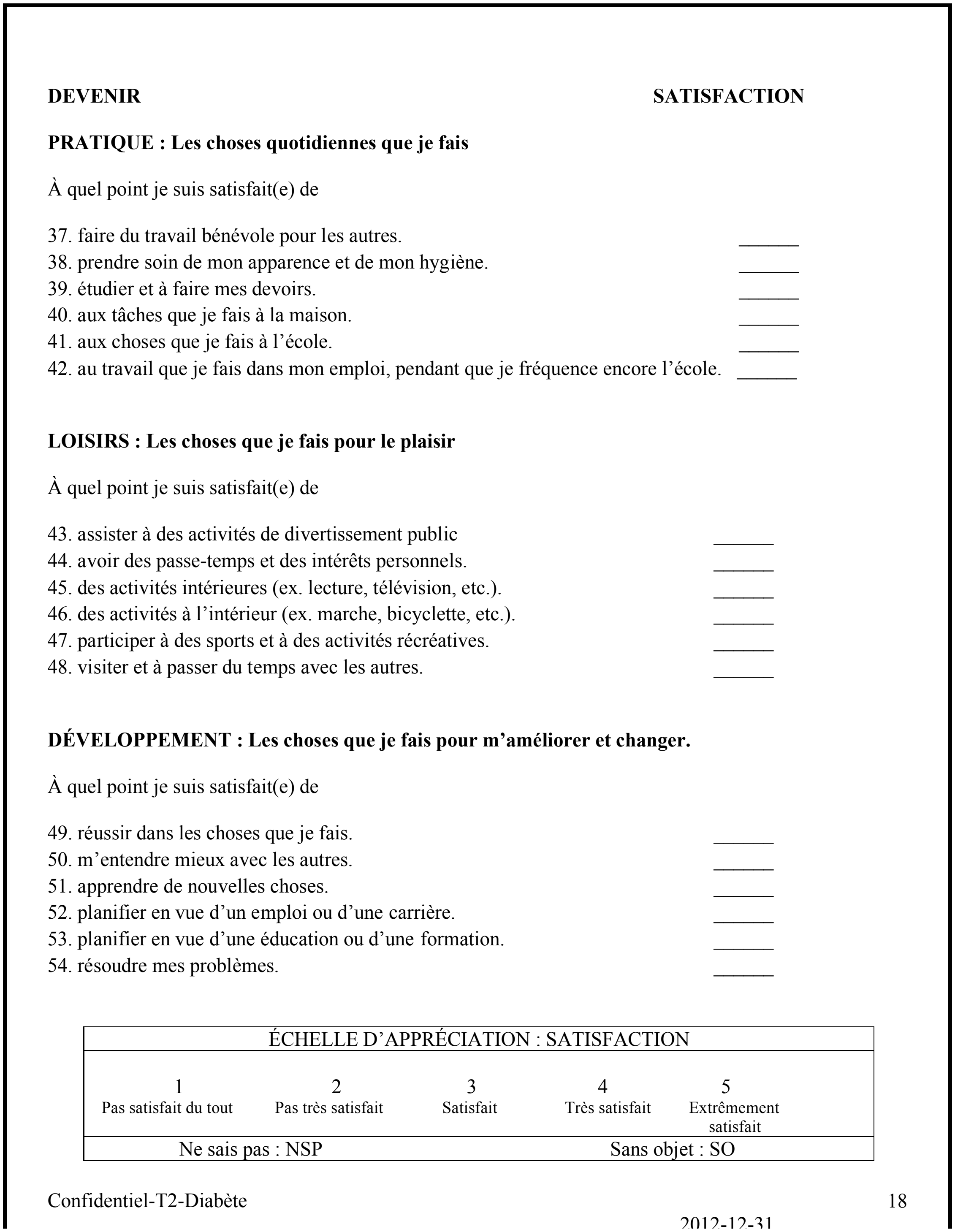
25. agir de façon responsable envers les autres. ______
26. être apprécié(e) des autres. ______
27. m'entendre avec ma famille. ______
28. avoir une copine ou un copain (blonde / chum). ______
29. faire des fêtes et avoir des choses à faire. ______
30. aux amis(es) que j'ai. ______

COMMUNAUTÉ : Mon accès aux choses

À quel point je suis satisfait(e) de

31. être capable d'aller chercher des services médicaux et sociaux tout(e) seul(e). ______
32. recevoir une bonne éducation. ______
33. avoir assez d'argent. ______
34. avoir des emplois disponibles pendant que je fréquente encore l'école. ______
35. avoir des endroits où aller avec mes amis. ______
36. avoir des choses à faire dans ma communauté dans mon temps libre. ______

ÉCHELLE D'APPRÉCIATION : SATISFACTION				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			Sans objet : SO	



DEVENIR **SATISFACTION**

PRATIQUE : Les choses quotidiennes que je fais

À quel point je suis satisfait(e) de

37. faire du travail bénévole pour les autres. ______
38. prendre soin de mon apparence et de mon hygiène. ______
39. étudier et à faire mes devoirs. ______
40. aux tâches que je fais à la maison. ______
41. aux choses que je fais à l'école. ______
42. au travail que je fais dans mon emploi, pendant que je fréquence encore l'école. ______

LOISIRS : Les choses que je fais pour le plaisir

À quel point je suis satisfait(e) de

43. assister à des activités de divertissement public ______
44. avoir des passe-temps et des intérêts personnels. ______
45. des activités intérieures (ex. lecture, télévision, etc.). ______
46. des activités à l'intérieur (ex. marche, bicyclette, etc.). ______
47. participer à des sports et à des activités récréatives. ______
48. visiter et à passer du temps avec les autres. ______

DÉVELOPPEMENT : Les choses que je fais pour m'améliorer et changer.

À quel point je suis satisfait(e) de

49. réussir dans les choses que je fais. ______
50. m'entendre mieux avec les autres. ______
51. apprendre de nouvelles choses. ______
52. planifier en vue d'un emploi ou d'une carrière. ______
53. planifier en vue d'une éducation ou d'une formation. ______
54. résoudre mes problèmes. ______

ÉCHELLE D'APPRÉCIATION : SATISFACTION				
1 Pas satisfait du tout	2 Pas très satisfait	3 Satisfait	4 Très satisfait	5 Extrêmement satisfait
Ne sais pas : NSP			Sans objet : SO	

CONTRÔLE

Combien de contrôle est-ce que j'ai sur

1. mon corps et ma santé physique. ______
2. mes pensées et mes émotions. ______
3. mes croyances et mes valeurs. ______
4. où je vis et où je passe mon temps. ______
5. les personnes autour de moi. ______
6. mon accès aux choses dans ma communauté. ______
7. les choses pratiques que je fais. ______
8. les choses que je fais pour le plaisir et l'amusement. ______
9. les choses que je fais pour me débrouiller et pour changer. ______

ÉCHELLE D'APPRÉCIATION : CONTRÔLE				
1 Aucun	2 Un peu	3 Un certain contrôle	4 Assez	5 Beaucoup
Ne sais pas : NSP			Sans objet : SO	

OCCASIONS

À quelle fréquence est-ce que j'ai l'occasion d'améliorer

1. mon corps et ma santé physique. ______
2. mes pensées et mes émotions. ______
3. mes croyances et mes valeurs. ______
4. là où je vis et où je passe mon temps. ______
5. les personnes autour de moi. ______
6. mon accès aux choses dans ma communauté. ______
7. les choses pratiques que je fais. ______
8. les choses que je fais pour le plaisir et l'amusement. ______
9. les choses que je fais pour me débrouiller et pour changer. ______

ÉCHELLE D'APPRÉCIATION : OCCASIONS				
1 Aucune	2 Peu	3 Quelques	4 Assez	5 Un grand nombre
Ne sais pas : NSP			Sans objet : SO	

Médicaments

A. Il arrive à tout le monde de ne pas prendre ses médicaments à un moment donné. Les énoncés qui suivent représentent des raisons communes pour lesquelles les personnes peuvent ne pas prendre leurs médicaments. À quelle fréquence ces raisons ont-elles fait en sorte que tu n’as pas pris tes médicaments? Indique un chiffre par énoncé en utilisant l’échelle suivante.

Très souvent	Souvent	Parfois	Rarement	Jamais
1	**2**	**3**	**4**	**5**

À quelle fréquence tu ne prends pas tes médicaments…

1. _____ quand tu n’es pas à la maison.
2. _____ quand tu te sens en santé.
3. _____ quand tu es occupé(e) avec autres choses.
4. _____ quand tu n’as plus de médicaments et que tu n’as pas renouvelé ta prescription.
5. _____ quand tu oublies tout simplement de prendre tes médicaments.
6. _____ quand tu n’as pas assez d’argent pour acheter les médicaments.
7. _____ quand tu déplaces ta bouteille de médicaments.
8. _____ quand d’autres personnes te disent que les médicaments ne sont pas bons.
9. _____ quand tu as trop de pilules à prendre.
10. _____ quand tu te sens mal après avoir pris les médicaments.
11. _____ quand tu en as simplement assez de prendre des pilules.

B. À quelle fréquence as-tu fait ce qui suit? Indique un chiffre pour chaque énoncé en utilisant l’échelle suivante.

Très souvent	Souvent	Parfois	Rarement	Jamais	Ne fait pas partie de mon traitement
1	**2**	**3**	**4**	**5**	**6**

1. _____ J’ai oublié de rapporter un problème particulier à mon médecin.
2. _____ Je n’ai pas pris de rendez-vous avec mon médecin ou à la clinique comme j’étais supposé(e).
3. _____ J’ai manqué des rendez-vous que j’avais pris avec mon médecin ou à ma clinique.
4. _____ J’ai oublié de téléphoner la clinique de diabète.

Renseignements démographiques

1. Date d’aujourd’hui : _______________

2. Lequel des énoncés suivants représente le mieux ta situation actuelle?
    a. Je suis étudiant (e) à temps plein et je ne travaille pas.
    b. Je suis étudiant (e) à temps partiel et je ne travaille pas.
    c. Je suis étudiant (e) à temps plein et je travaille à temps partiel.
    d. Je suis étudiant (e) à temps partiel et je travaille à temps partiel.
    e. Je travaille à temps plein.
    f. Je travaille à temps partiel.
    g. Autre : ____

3. Présentement, habites-tu chez tes parents? Non ___ Oui ___

4. Présentement, prends-tu des médicaments? _______________

5. Si oui, quels médicaments prends-tu?

____
____
____
____
____

6. As-tu vécu des changements importants dans la dernière année? (Exemple : déménagement, changement d’école, décès, arrêt d’éducation, etc.)?

____
____
____
____
____

7. Quels ont été pour toi les changements les plus positifs et/ou les plus négatifs qui ont été apportés suite à ta transition au milieu hospitalier adulte?

____
____
____
____
____

8. Y'a-t-il eu, selon toi, une ou des périodes difficile(s) à traverser suite à la transition au milieu hospitalier adulte? S'il te plaît, indique à quelle(s) période(s) approximativement tu as traversé cette(ces) difficulté(s).

____
____
____
____
____

9. Si tu as passé des moments difficiles, qu'est-ce qui t'a aidé à les traverser?

____
____
____
____
____

10. Y'a-t-il des ressources ou de l'aide additionnelle que tu aurais aimé avoir suite à la transition au milieu adulte?

____
____
____
____
____

11. Sur une échelle de 0 à 10, indique à quel degré tu es satisfait(e) de ton expérience de transition (encercle).

0	1	2	3	4	5	6	7	8	9	10
Pas du tout										Tout à fait

12. Sur une échelle de 0 à 10, indique à quel degré tu penses t'être adaptée au milieu hospitalier adulte.

0	1	2	3	4	5	6	7	8	9	10
Pas du tout										Tout à fait