Postoperative Recovery after Spinal Fusion Surgery (PR-SF):

A prospective study in adolescents with idiopathic scoliosis and their parents.

Research Protocol

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INTRODUCTION

A. PROJECT BACKGROUND AND SIGNIFICANCE.

Chronic and recurrent pain is a common health problem among children and adolescents [3]. While most children/adolescents experience low levels of disability, a significant number report moderate to severe restrictions in their daily functioning [4], ranging from lowered levels of physical activity [5], to increased absence from school [6,4] and fewer friends [7]. To better understand the origins and persistence of chronic pain in adults [8] and children [9,1,10], researchers have frequently relied on the Fear-Avoidance Model (FAM). At the core of this cognitive-behavioral model is the idea that catastrophic thoughts about pain may set the stage for pain-related fear, which, in turn, may motivate individuals to behave in ways that allow them to avoid pain. Yet, evidence shows that attempts to avoid pain often leads to maladaptive consequences, such as disability and depression [1]. Although the majority of work in this area has focused on adult pain [8], recent evidence suggests that the very same processes may also be central to the development and maintenance of pediatric pain and disability [9,1,10].

Additionally, over the past decades, research has shown that (pediatric) pain is not only a private experience, but one that takes place in a wider social context [20,21]. In the context of pediatric pain, for example, the role of others is very salient as children are especially dependent upon (meaningful) adults (i.e. parents) for care and help. Recently, an extension of the FAM, the Interpersonal Fear-Avoidance Model (IFAM) has emerged and highlights the impact that parents have upon the development and maintenance of (chronic) pediatric pain [22]. This model posits that parents who perceive their child's pain as very threatening (i.e. have high levels of catastrophic thoughts about the child's pain) tend to experience high distress and fears regarding that pain. This distress motivates parents to engage in behaviors aimed at avoiding, reducing or controlling their child's pain. These behaviors are often referred to as "protective parenting behaviors" (e.g. keeping the adolescent home from school, frequent monitoring of the adolescent's pain). At the same time, parents' worries and fears may fuel child's worries/fears through observational learning processes [23], and impact the child's own tendencies to avoid activities expected to induce pain. In line with this model, accumulating evidence indicates that parents often have catastrophic thoughts about their child's pain [24,25] and experience high levels of distress when faced with their child's pain [24], which may motivate them to engage in "protective parenting" behaviors [24,26,27]. Although protective parenting behaviors may seem like a natural and adaptive response to adolescent pain, evidence suggests that such efforts are often associated with miscarried helping endeavors [28] and

maladaptive childhood outcomes such as increased functional disability [27] and decreased school attendance [29].

Although the (I)FAM has rapidly accelerated our understanding of (pediatric) chronic pain it has been subject to criticism in recent times. Several authors argue that the model has focused too narrowly on catastrophizing/fear/phobias and their relation to a single goal (pain avoidance), and that pain should be viewed within a context of multiple goals (not only pain reduction) [11]. Indeed, the successful attainment of developmental goals and adequate functioning may depend on the ability to behave in ways that allow people to reach important goals (e.g., academic achievement), despite the persistent presence of pain [1]. Others argue that the FAM cannot explain why individuals develop fears for situations which they have not experienced before (i.e., through indirect learning) [12]. Finally, other researchers have indicated that the FAM is mainly concerned with prediction of pain and remains vague in delineating processes of recovery [13]. In the present project we will draw on a modern functional approach, known as Relational Frame Theory (RFT, [14,15,16]) to address these limitations and expand the current literature on the development and maintenance of chronic pain in children. RFT is an influential theory of human language and cognition within a tradition known as Contextual Behavioral Science (CBS). CBS takes the view that behavior is an 'act-in-context' which can only be understood by examining the antecedent settings or context in which it occurs as well as consequences that give rise to and maintain it. By 'act' we mean both the private (e.g., catastrophic thinking about pain) and public ways in which children can behave (e.g., facial pain expression) while 'context' refers to the current and historical settings or environments in which that behavior has previously occurred.

B. STUDY BACKGROUND AND OBJECTIVES.

In this section more specific background information and objectives of one clinical study that is part of the abovementioned described global PhD-project will be discussed. In the following sections, the protocol (i.e. hypothesis, measures, data collection methods,…) of this prospective postoperative study will be discussed in more detail.

Adolescent Idiopathic Scoliosis (AIS) is one of the most common forms of scoliosis. 'Idiopathic' refers to the fact that medical science has not (yet) discovered any causal factors that might explain the exact etiology of this disease. AIS is the type of scoliosis that is most often seen in adolescents. Moreover, it seems to affect more girls than boys. AIS is mainly clinical diagnosed, it can easily be detected by the observation of the adolescent's S-shaped

body posture and *gibbus* deformity. Subsequently, the severity of this S-shape needs to be investigated by means of screening a radiographic picture among other things. If a Cobb angle of 10 degrees or more (i.e. a way of measuring the severity of the scoliosis) is observed, the adolescent gets an AIS diagnosis. If this angle evolves and reaches 20 degrees, the specialist will consider possible treatment options, driven by the main objective to stop or retard the scoliosis' (negative) evolution. The first choice treatment is regular observation of this evolution by the specialist. In a second stage (i.e. if the Cobb angle reaches the level of 25 to 45 degrees), the adolescent can be asked to wear a brace around the back together with continued regular appointments in order to observe any further evolution. If the scoliosis (i.e. Cobb angle) reaches a level of 45 degrees or higher, the need for surgical treatment to stabilize and correct the scoliosis will be discussed with the adolescent and his/her family. Moreover, when breathing difficulties, problems with sitting or aesthetical problems (i.e. because of the observable marked body deformity and potentially related self-image issues) are present, this might give additional reasons to consider surgery.

Normally, patients with AIS do not experience any pain due to their scoliosis (i.e. before the surgery). However, this does not exclude that these patients might experience back pain due to other causal factors. It is even the case that if patients do experience back pain, the underlying reason for this needs to be investigated and treated if possible. For example, this might be due to a bone tumor or can be regular low back pain (which is observed in about 20 % of all children and adolescents [18,19]. After this major surgery, patients will however experience a lot of acute postoperative pain due to the invasiveness of the orthopedic surgical procedure. At the hospital this acute pain is precisely treated and monitored by the pediatric doctor, nurses and responsible anesthetist (i.e. following a specific pain treatment protocol which is systematically evaluated). Until now, some studies have shown that in some cases this acute postoperative pain can become chronic (i.e. persistent pain for longer than 6 months) [2,17]. One recent study [2] shows different pain and related functioning trajectories following the surgery for a period of five years. As with other types of chronic pain, this pain can become disabling after time and this can have adverse effects upon the child's general psychosocial functioning (i.e. self-image, affect, engagement in activities,…) and his/her postoperative recovery process (e.g. duration, speed, complications,…). Since there are little studies [2,17] that have specifically investigated adolescent's postoperative functioning after spinal fusion surgery and great variability in functioning is shown (i.e. 4 different pathways of pain-related functioning), this calls for additional studies looking at which factors might explain or even predict this variability. In this

study we want to investigate our abovementioned general research objectives with respect to the postoperative (pain-related) recovery process of adolescents with AIS who underwent posterior spinal fusion surgery. We aim to add to the knowledge about the postoperative functioning of AIS patients and aim to give explanations for potential different recovery pathways.

A first aim is to investigate possible risk and resilience factors that are predictive for the adolescent's postoperative recovery. A primary objective within this aim is to focus on the factors that are central to the PhD-project. Specifically, we will explore adolescent's psychological flexibility and acceptance of postsurgical pain as potential resilience factors predicting better recovery. On the other hand pre-surgical pain intensity and pain catastrophizing will be explored as potential risk factors increasing the possibility of poor recovery. . The recovery process will be assessed by measures of the adolescent's pain and his/her health-related functioning and physical activity levels. after surgery. A secondary objective within this aim is to examine pre- and per-operational parameters (e.g. Cobb's angle, length of fusion, complications, …), general optimism, positive affect, pain-related fear and pre-surgical as potential predictors for the adolescent's recovery process.

A second aim is to examine the role of the interpersonal context in which the adolescent is recovering, upon the adolescent's postoperative recovery. As a primary objective within this aim we will specifically look at potential risk and resilience factors at the level of the parent. On the one hand we will look at the possible beneficial influence of parental psychological flexibility, general positive affect an optimism about the future on the adolescent's postoperative functioning. On the other hand we will assess parents' maladaptive thoughts and feelings (about the adolescent's pain) and (protective and solicitous) behaviors towards the recovering adolescent and examine if these are increasing the risk for negative outcomes. A secondary objective is to examine other parental predictors (e.g., pain-related fear, optimism, positive affect) as predictors of adolescent recovery.

A third and final aim further builds on the ones described above and is to examine the potential *buffering* role of the adolescent and parent resilience factors, that is to examine if these factors moderate adolescent daily pain-related behavior during the recovery process and more specifically, if they mitigate or reduce the negative influence of the proposed risk factors on adolescent pain-related functioning.

METHODS

A. STUDY DESIGN, SETTING AND PARTICIPANTS

I. Study Setting and Design

This study is a prospective longitudinal study (i.e. *measurement burst design*) that has been conducted by researchers from the Department of Experimental Clinical and Health Psychology (i.e., Prof. dr. Liesbet Goubert, dr. Sean Hughes, and Melanie Beeckman (PhD student)) and researchers from the Department of Physical therapy and motor rehabilitation (i.e. Prof. dr. Lieven Danneels and dr. Mieke Dolphens) from Ghent University. For this study we have recruited eligible AIS patients and (one of) their parents in collaboration with multidisciplinary teams (i.e. orthopedic surgeon, anesthetist and pediatricians) from four (university) hospitals in Flanders where posterior spinal fusion surgery is performed with adolescents who are diagnosed with idiopathic scoliosis. The central hospital is the University Hospital of Ghent and (orthopedic surgeon: Prof. Dr. Frank Plasschaert). The other collaborating hospitals are the the General Hospital St-Jan at Bruges (orthopedic surgeon: Prof. Dr. Frank Plasschaert), the University Hospital of Antwerp (orthopedic surgeon: Dr. Jozef Michielsen) and the University Hospital of Leuven (orthopedic surgeon: Prof. Dr. Pierre Moens).

II. Eligibility Criteria

Eligible participants for our study are adolescents:

- who are diagnosed with Adolescent Idiopathic Scoliosis (AIS)
- are aged between 11 and 18 years
- who are scheduled for their first posterior spinal fusion surgery (inclusion criteria for surgery: Cobb Angle > 45°, skeletal maturation (unless progressive curve); *criteria might differ between surgeons*)
- who recently underwent a posterior spinal fusion surgery and still visit the hospital for follow-up meetings (inclusion between 3 weeks and 6 months after surgery)
- of whom one of their parent(s)/primal caregiver is also willing to participate in the study. **Note:** adolescent participants can participate without a participating parent. However, parental consent is always required.

Participants will be **excluded** from the study if:

- they are diagnosed with congenital or neuropathic scoliosis

- they do not meet the criteria to have surgery (i.e. Cobb Angle < 40°, stable curve, no skeletal maturation; *criteria might differ between surgeons*)
- they decide to do not have surgery (during the study)
- they are scheduled for combined or anterior spinal surgery
- they already underwent surgery for their scoliosis in the past
- they do not have sufficient Dutch language reading, understanding and/or speaking skills

III. **Predictors and Outcomes**

Table 1: Adolescent Constructs, Measures and Role in Analyses – Measured before Surgery (T0)

Construct	**Measure(s)**	**Scores used as variables**	**Role in analyses**
Demographics	Demographic questionnaire (child + parent)	Age, gender, ethnic background, educational level, hospital center + surgeon	Descriptive / Control
Biomedical variables	Medical record/Questionnaire	Pre, peri- and postoperative variables	Descriptive /Control
Physical variables	Radiographic data (biomedical questionnaire)	Flexibility/Mobility	Predictor
Physical activity	Flemish Physical Activity Questionnaire (FPAQ-adolescent & child version)	*Subjective* measure of physical activities in several domains. *Total score.* *Objective* measure of physical activity – light, moderate, vigourous	Baseline

Psychological flexibility	<u>Open</u> Action and Fusion Questionnaire (AFQ-Y) <u>Aware</u> Children's and Adolescent's Mindfulness Measure (CAMM) <u>Engage/action</u> Willingness and Action Measure (WAM-C/A)	*Total score:* Psychological inflexibility Subscales: *Cognitive fusion, experiential avoidance, behavioral effectiveness (subscale score)* *Total score*: mindfulness *Total score*: willingness & action	Predictor Moderator
Trait Optimism	Youth Life Orientation Test (Y-LOT)	*Total score:* Optimism	Predictor
(Trait) Affect	Positive and Negative Affect Scale (PANAS-A)	*Subscale scores:* Positive & Negative affect	Predictor
Self-image	SRS-22r - self-image	*Subscale score:* item 4 + item 6 + item 10 + item 14 + item 19	Predictor
Pain Catastrophizing	Pain Catastrophizing Scale for Children	*Total score:* Pain Catastrophizing	Predictor
Pain	Von Korff (Graded Chronic Pain Scale – Children)	*Subscale scores:* Pain intensity + Pain Disability (in the past 3 weeks)	Baseline
Functioning	Pediatric Health-related Quality of Life Inventory	*Total score:* Global Health-related functioning	Baseline

	(PedsQL 8-12/PedsQL 13-18) Functional Disability Inventory	*Subscale scores:* Physical Functioning + Psychosocial Functioning (emotional, social, school) *Total score:* Functional Disability	
Treatment	SRS 22r– satisfaction with management Patient's preoperative expectations	*Item 21 + item 22* 9 items	Predictor
Well-being	PROMIS – depressive symptoms (SF 8b) PROMIS – relation with peers (SF 8a)	*Total scores*	Predictor/ Baseline
Daily functioning	1-week daily diary	*Average scores, day-to-day relations, variability* - mood - pain intensity - pain-related thoughts, emotions & behavior - psychological flexibility - planned activities + interference - report on parental reactions to pain (instructions to avoid/engage in activities)	Predictor

Table 2: Parent Constructs, Measures and Role in Analyses – Measured before Surgery (T0)			
Construct	**Measure(s)**	**Scores used as variables**	**Role in analyses**

Demographics	Sociodemographic questionnaire	Age, gender, ethnicity, parent marital status, parent educational background, occupation	Descriptive
Parents' Psychological Flexibility	Avoidance and Action Questionnaire (AAQ-II; 7 items) Parental Acceptance Questionnaire (6-PAQ)	*Total score:* Psychological (In)flexibility *Subscale scores:* Cognitive fusion, Experiential Avoidance, Behavioral (In)effectiveness *Total Score:* Parental Psychological Flexibility in Parenting. *Subscale scores*: Acceptance, Defusion, Being Present, Self-as-context, Values and Committed Action	Predictor
Trait Optimism	Life Orientation Test (LOT-R)	*Total score*: Trait Optimism	Predictor
Trait Affect	Positive and Negative Affect Scale (PANAS)	*Subscale scores:* Positive and Negative affect	Predictor
Pain catastrophizing/fear of pain	Pain Catastrophizing Scale for Parents (PCS-P)	*Total score:* Parental Catastrophizing about Child Pain	Predictor
Parenting Behavior	Overprotective Parenting Scale (OPS) (adolescent report/parent report) Parenting Dimension Scale (adolescent report/parent report) Inventory of parent's	*Selection of subscales:* Anxiety-driven Parenting, Premature Problem-solving, Babying *Subscale scores:* Autonomy Support, Responsivity Psychological control *Subscale scores:*	Predictor

	responses to adolescent/child pain experiences (IRPEDNA) (parent report)	Solicitousness, Discouragement, Promotion of Well-Behaviors	
Daily functioning	1-week daily diary	*Average scores, day-to-day relations, variability* - mood - thoughts, emotions about child pain - reactions to pain (instructions to avoid/engage in activities)	Predictor

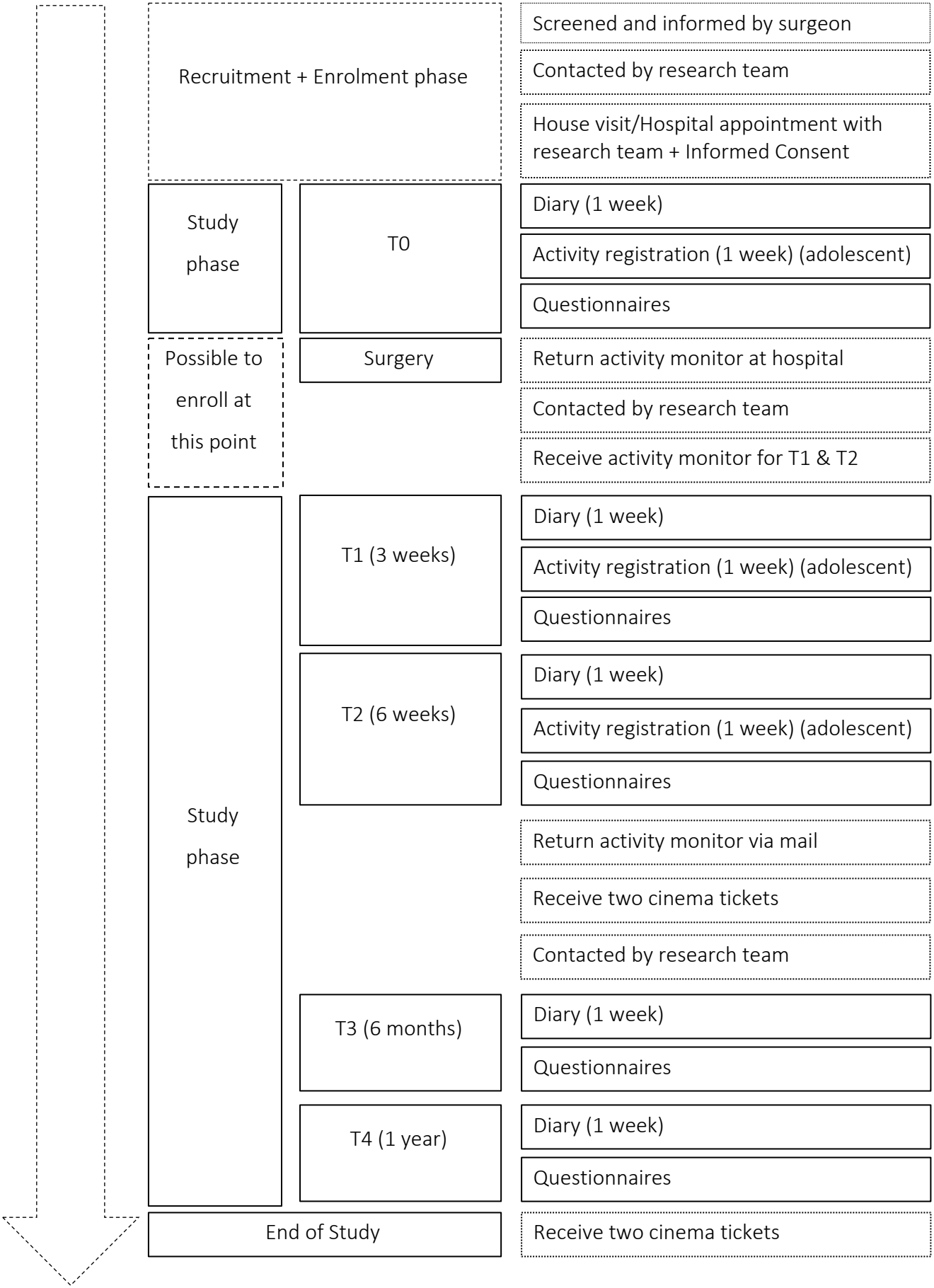
Table 3: Parent and Adolescent Constructs, Measures and Role in Analyses at Follow-up (T1-T4)			
T1: 3 weeks; T2: 6 weeks			
Construct	**Adolescent Measure(s)**	**Scores used as variables**	**Role in analyses**
Pain	Graded Chronic Pain Scale (Von Korff)	*Subscale scores:* pain intensity (in past 3 weeks) pain disability (in past 3 weeks)	Predictor /Outcome
Functioning	Functional Disability Inventory (FDI) (child/parent report) Pediatric Health-Related Quality of Life Inventory (PedsQL) (child/parent report)	*Total score:* Functional Disability *Total score:* Global Health-related functioning *Subscale scores:* Physical Functioning + Psychosocial Functioning (emotional, social, school)	Predictor/Outcome
Physical activity	Flemish Physical Activity Questionnaire (FPAQ-adolescent & child version)	*Subjective* measure of physical activities in several domains. *Total Score*	Predictor/ Outcome

Pain-related Psychological Flexibility	Chronic Pain Acceptance Questionnaire (CPAQ-A)	*Total Score:* Chronic Pain Acceptance	Predictor
Daily functioning	1-week daily diary (child & parent)	*Average scores, day-to-day relations, variability*	Predictor/Outcome
Construct	**Parent Measure(s)**	**Scores used as variables**	**Role in Analyses**
Pain-related Psychological Flexibility	Parental Psychological Flexibility Questionnaire (PPFQ) Parental Pain Acceptance Questionnaire (PPAQ)	*Total score:* Parental Psychological Flexibility about Child Pain *Subscale scores:* Acceptance, Committed action, Cognitive Defusion *Total score:* Parental Acceptance of Child Pain	Outcome
T3: 6 months			
Construct	**Child Measure(s)**	**Scores used as variables**	**Role in analyses**
Pain	Graded Chronic Pain Scale (Von Korff)	*Subscale scores:* pain intensity (in past 3 weeks) pain disability (in past 3 weeks)	Predictor /Outcome
Functioning	Functional Disability Inventory (FDI) (child/parent report) Pediatric Health-Related Quality of Life Inventory (PedsQL) (child/parent report)	*Total score:* Functional Disability *Total score:* Global Health-related functioning *Subscale scores:* Physical Functioning + Psychosocial Functioning (emotional, social, school)	Predictor/Outcome

Physical activity	Flemish Physical Activity Questionnaire (FPAQ-adolescent & child version)	*Subjective* measure of physical activities in several domains. *Total Score* *Objective* measure of physical activity. Light – moderate – vigorous	Predictor/ Outcome
Daily functioning	1-week daily diary (child & parent)	*Average scores, day-to-day relations, variability*	Predictor/Outcome
T4: 1 year			
Construct	**Child Measure(s)**	**Scores used as variables**	
Pain	Graded Chronic Pain Scale (Von Korff)	*Subscale scores:* pain intensity (in past 3 weeks) pain disability (in past 3 weeks)	Outcome
Functioning	Functional Disability Inventory (FDI) (child/parent report) Pediatric Health-Related Quality of Life Inventory (PedsQL) (child/parent report)	*Total score:* Functional Disability *Total score:* Global Health-related functioning *Subscale scores:* Physical Functioning + Psychosocial Functioning (emotional, social, school)	Outcome
Physical activity	Flemish Physical Activity Questionnaire (FPAQ-adolescent & child version)	*Subjective* measure of physical activities in several domains. *Total Score* *Objective* measure of physical activity. Light – moderate – vigorous	Outcome

Daily functioning	1-week daily diary (child & parent)	*Average scores, day-to-day relations, variability*	Outcome
Post-operative scoliosis-specific functioning	SRS-24 – *postoperative*	7 postoperative item scores	Outcome

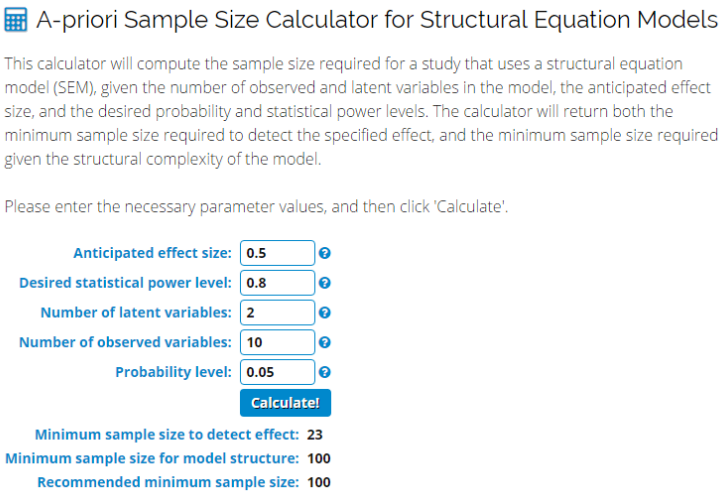
IV. **Participant Timeline**



V. Sample Size

We aim to include at least 100 patients aged between 11 and 18 with an adolescent idiopathic scoliosis diagnosis (AIS) who are scheduled for a posterior spinal fusion surgery and one of their parents.

Power & sample size considerations. For the SEM-analyses (see below) the required sample size to have a power level of at least 80 % was calculated by means of an online tool. With each hypothesis no more than 10 observed variables and 1 or 2 latent variables (e.g. general functioning) will be investigated. A minimum sample size of 100 participants will give this study at least 80 % power to detect (a) standardized effect(s) of .50 at the 5 % significance level.



For the multilevel analyses of the diary data, this study, with 120 participants and 35 measurement moments, has more than 90 % power to detect a standardized effect of .15 at the 5 % significance level at the within-subject level.

VI. Recruitment and Enrollment phase

Children and their parents were informed about the study for the first time at their first pre-surgical consultation with the orthopedic surgeon. The surgeon gave them a short introduction about the study's design and primary aims. If they were interested to participate, the surgeon wrote down the family's contact information (e.g. telephone number and/or e-mail address). Also, the surgeon designated this on the document that is send to the responsible research team member at the hospital (e.g., nurse, assistant, clinical staff). This research team member was responsible for giving this information to the principal investigator at the university of Ghent. This information was transferred via a shared and secured response rate file (i.e. names + contact information of each family) and saved at a protected computer of the university.

Information about the pre- and post-surgical consultations of the families who participated was also communicated via this shared file. A study information letter was provided at the initial contact with the surgeon and/or the research team member at the hospital.

In the time between the first consultation and the day of pre-operative investigations, someone of the university's research team contacted the patient and its parents (all communication was primarily done via the parent of the under-aged adolescent). During this conversation, the family was provided with more information about the study and there was room to ask questions. At this point, patients could either decide to participate or withdraw their participation. If they agreed to participate, a house visit or appointment at the hospital was planned depending on the availabilities of the family and someone of the research team and the date of the pre-operative investigations. All necessary contact information (telephones, e-mail, postal address) was gathered during this conversation and registered in a response rate document. This response rate document was shared with all university's research team members (principal investigators + master students). If the family did not receive an information letter yet, this was sent to them via e-mail after this telephone conversation. In all cases, an e-mail with the confirmation of the appointment details (place, date, hour) was sent to the families after this conversation.

The university's research team kept track of the recruitment flow of participants in a shared response rate document which contained the names of the eligible participants, if they are interested in participating, if, when and how many times they have been contacted by somebody of research's team, if they agreed to participate and the agreed moment for the house visits. If they participated other information such as start and end dates of each measurement moment, the number of activity monitoring device, if and when these devices were sent and returned, if and when cinema tickets were sent, if and when diaries were started, and if and when questionnaires were completed.

Informed consent was retrieved via a question in the first diary of the first diary registration week. All adolescent participants were asked to give their informed assent, while all parents were asked to both consent for their own participation as well as for the participant of their under-aged child.

B. DATA COLLECTION, MANAGEMENT AND ANALYSIS.

I. **Data Collection Methods**

1. DATA COLLECTION PROCEDURE

Data was collected at five points in time: 2-3 weeks before the surgery (T0), 3 weeks after surgery (T1), 6 weeks after surgery (T2), 6 months after surgery (T3) and 12 months after surgery (T4). At each point in time both daily diary as well as questionnaire data of the parent and the adolescent were collected. Objective physical activity data of the adolescent was collected at T0, T1 and T2.

All the questionnaires an diary registrations (i.e. at each point in time) were administered online through Limesurvey [58], a protected web-based survey tool/server to obtain research data. Adolescents and their parent were asked to complete the diary and the questionnaires at each point in time before and after the surgery (i.e. T0-T4) online at their computer at home. If they did not have access to the internet or a computer at home, the diaries and the questionnaires were completed on a paper version. The paper versions of these questionnaires were then mailed to the families in a pre-stamped envelope so that they could send them back to the researchers without any costs. The corresponding day and dates of the diary were written on the documents by the researcher before they were sent to the families.

Diary. At each pre- and postoperative measure point (T0-T4) both the adolescent and the parent were asked to keep an online diary on a daily basis in the evening for a period for seven consecutive days. The adolescent and his/her parent each received a personal code to access their own diary. At each measure point participants received an e-mail reminding them of the diary registration week. Both parent and adolescent received a link and a personal code to get access their own diary. Participants were asked to complete the diary for 7 consecutive days. Preferably they started on Monday and completed their last diary on Sunday, as this was easier for the research team to follow up. Participants were reminded daily to complete their diary via automatically send text messages (if they agreed to receive this). Someone of the research team did a daily check in the morning to see if the diaries were completed and – if not yet completed - reminded the participants via text message that they could still complete the diary before 10 am the next day.

Physical Activity Registration. At T0, (adolescent) participants received the activity monitoring device during their appointment with someone of the research team. During this appointment the necessary instructions were given to use the monitoring device correctly. All

participants were asked to wear the device around their waist and at the right side of their body. Participants were asked to wear this device during the whole registration week. They were asked to wear it during the day and at night, but were given the possibility to take out the device at night if it was too uncomfortable to sleep with. Furthermore, they were asked to not wear the device when they went swimming or did (heavy) sports that would increase the risk for damaging the device. In the daily diary, a tool was provided where participants could complete the following information: the moment when they started wearing the device, the moment when they took it off and the reason for taking it off. As such they could provide us the exact information on non-wear time of the device. The monitoring device has no on/off switch and was each time set up by someone of the research team to start and end registration at specific dates and times. All this information was also written down in a instruction leaflet. Finally, the parents were asked to sign an "agreement of use" for this device, in which they agreed with terms of use. They were not held responsible for financial reimbursement of any costs if the device was damaged. After the first registration week (T0) participants were asked to bring the device with them to the hospital on the day of the surgery and hand it over to a research team member or their surgeon. A member of the university's research team collected the devices in the hospital or they were send to the university via mail. The activity monitoring device for T1 and T2 was either delivered to the participants during their post-op consultation at the hospital, or was send to them via mail. Participants were instructed to wear the device during the registration week at T1 and T2. In the weeks in between these two measurement moments they were asked to take the device off and keep it at a save place at their home. They were also instructed to charge the device before the start of each week. After the third registration week (T2) participants were asked to send the device back to the researcher via mail or give it back to the research assistant in the hospital during their post-operative consultations. If they choose to send it back via mail this was done via a delivery agency and the transport costs were paid by the principal investigator. Participants were reminded about wearing the activity monitoring device in the same e-mail containing information about the diary at T0, T1 and T2.

Questionnaires. Participants were asked to complete a set of questionnaires at the end of each registration week. The link and code to get access to this questionnaires was again sent to them via e-mail. All participants are asked to complete the questionnaires within the week after receiving this e-mail. At T0, participants were specifically asked to complete the questionnaires at the latest on the day *before* their surgery. At T1, they were asked to complete the set of questionnaires at the latest before the start of the registration week at T2. Completion of the

questionnaires was regularly checked by someone of the research team. Reminder e-mails were sent if they were not completed after one week (or if they were not completed at 2-3 days before the surgery). If they were still not complete, participants were reminded about this via telephone. A maximum of 3 reminder e-mails were sent to each family. If a family did not have free access to the internet or a computer at home, they were given the exceptional option of completing the questionnaires on paper at home. These packages were send to them in pre-stamped envelopes, and they were asked to send them back within two weeks after receiving them.

2. OVERVIEW OF THE MATERIALS

Method 1: Follow-Up Diary

The diary was accessible via an online web-based diary/survey tool (LimeSurvey[58]). Participants were asked to answer a same set of questions on a daily basis at each measurement point (T0-T4). At the beginning of each diary they were asked to complete all items at once. The majority of the items were answered on a 7-point response scale (0: not at all true; 6: totally true) unless indicated otherwise (see Table 4 and 5). Some of the items were conditional on the answer on previous items (see Table 4 and 5).

The diary items were developed based on items of questionnaires that were validated to measure the construct and adjusted for use on a daily basis. If applicable, the source questionnaires for the items are each time provided in Table 4. Content analysis

Table 4: Constructs, Number of Items, and Item + Scales of the Adolescent Diary

Construct	# **items**	**Items + scale**	**Source**
Mood	10	Positive: *Joyful, Cheerful, Happy, Lively, Proud* Negative: *Miserable, Blue, Afraid, Scared*	Positive and Negative Affect Schedule for Children (10-item; Ebesutani et al, 2012, Dutch translation based on De Bolle et al., 2010)
Self-Image/Satisfaction with body	1	*Today, I felt satisfied with how I look.* (0: not at all true; 6: totally true)	
Fatigue	1	*How tired were you on average today?* (0: not tired; 6:	

		worst possible tiredness	
General Functioning	6	- *Which activities did you planned to do today?* *Activities that have something to do with…* (multiple choice item; options: school, friends, family, hobby's, sport, household chores, others (space to provide details). - *Did you do less or more than the activities that you had planned?* (-3: far less activities, 0: did what I planned to do; +3: far more activities) - *I have experience difficulties with doing this activities today* (0: not at all true; 6: totally true)	
School attendance	1	*Did you attend a full day (or a half day on Wednesday) of school today?* (yes/no) (conditional item) -> if yes: continue -> if no: *Why did you not attend a full day of school?* (option 1: There was no school because it is a holiday or weekend; option 2: I did not attend school because of the pain or other physical complaints; option 3: other (option to provide details)	

Pain Intensity	2	- *How intense was your pain on average today?* (0: no pain; 6: worst possible pain) - *How intense was your worst pain today?* (0: no pain; 6: worst possible pain)	Graded Chronic Pain Scale for Children (Von Korff, 1992; Dutch version, Vervoort, 2014) – two items of the *characteristic pain intensity subscale*
Physical complaints	1	*Did you experience other physical complaints today?* (0: no complaints; 6: a lot of other complaints) (conditional item) -> if no: continue -> if yes: *If yes, which other physical complaints* (space provided to give details)	
Pain interference	1	*Today, I had difficulties with doing my activities because of the pain or other physical complaints* (0: not at all true; 6: totally true)*	Based on pain interference items (Graded Chronic Pain Scale - *disability* subscale)
Activity-Engagement	3	-*Today, I did my planned activities while I was in pain or had other physical complaints* (0: not at all true; 6: totally true)* - *Today, it was important for me to (at least try) to do my activities while I was in pain or had other physical complaints* (0: not at all true; 6: totally true)* - *Today, I did my best to do the activities that I find important or fun to do while I was in pain*	Chronic Pain Acceptance questionnaire for adolescents (McCracken et al., 2010; Wallace et al., 2011) – *Activity Engagement subscale*

		or had other physical complaints (0: not at all true; 6: totally true)* * <u>conditional items</u> on items about pain and physical complaints. Not shown participant reported no pain AND no physical complaints.	
Avoidance of activities	3	- *Today, I skipped activities because I thought the pain or other physical complaints would worsen by doing so* (0: not at all true; 6: totally true) - *Today, I stopped with what I was doing because the pain or other physical complaints started or became worse* (0: not at all true; 6: totally true) - *Today, I took some rest instead of doing activities because of (potential) pain or other physical complaints* (0: not at all true; 6: totally true)	Fear of Pain Questionnaire (Simons et al., 2011) – *avoidance subscale*
Psychological Flexibility	3	- *Today, I was aware of and attentive for my feelings and thoughts* (0: not at all true; 6: totally true) - *Today, I was aware of and attentive for what happened around me* (0: not at all true; 6: totally true) - *Today, I allowed my negative feelings and thoughts*	Several measures of psychological flexibility. - *Avoidance and Fusion Questionnaire for Youth* (Greco et al; 2008a, 2008b; Livheim et al., 2016) - Based on DNA-V model (Hayes & Ciarrochi, 2015; Ciarrochi et al., 2016) - Aware (observing,

		to be there (0: not at all true; 6: totally true) - *Today, I was able to let of my negative feelings and thoughts* (0: not at all true; 6: totally true) - *Today, I did things which I find important* (0: not at all true; 6: totally true) - *Today, I'm satisfied with the things I have done* (0: not at all true; 6: totally true)	descriptive, awareness) – NOTICER - Open (acceptance, cognitive defusion) – DISCOVERER - Engage (commited action, value-based action) – ADVISOR/VALUE - Louise Hayes – Act with Teens
Presence of parent/guardian	1	*Did you have contact with this person today (e.g., in real life, via telephone, sms or e-mail)* (yes/no)	
Parent's Instructions (Avoidance – Engagement)	2	- *This person told me today to stop or cancel activities because of the pain or other physical complaints* (0: not at all true; 6: totally true)** - *This person has told me today to keep on doing fun or important activities (or any other activities I usually do) while I was in pain or had other physical complaints.* (0: not at all true; 6: totally true) **	*CPAQ – activity engagement* subscale (adjusted to parent instruction item) *Fear of Pain Questionnaire* – Avoidance subscale (adjusted to parent instruction item)
Parental Protective Behavior	2	- *This person has made sure I did not have to do certain activities (e.g., household*	Items based on items of the Inventory/caregiver responses to the children's pain

		chores, going to school, or sports) because of the pain or other physical complaints. (0: not at all true; 6: totally true)** - *This person cancelled his/her activities (e.g., job-related duties, household chores, and/or hobbies) to be with me* (0: not at all true; 6: totally true)** ** <u>conditional items:</u> these items are only shown if the child indicates to have had (any form of) contact with the parent/guardian	experiences (IRPEDNA; Huguet et al., 2008) – *solicitous behavior subscale*
Pain Catastrophizing	3	- *Today, I thought something serious might happen to me because of the pain* (0: not at all true; 6: totally true) - *Today, I kept thinking about how much pain I was experiencing* (0: not at all true; 6: totally true) - *Today, I felt I couldn't go on much longer because of the pain* (0: not at all true; 6: totally true)	Pain Catastrophizing State items (validated by Durand et al., 2017)
Pain-related fear	3	- *Today, my pain caused my heart to beat fast or race* (0: not at all true; 6: totally true) - *Today, feelings of pain were scary for me* (0: not at all true; 6: totally true)	Fear of Pain Questionnaire – *Fear subscale* (Simons et al., 2011)

		- *Today, I worried about my pain* (0: not at all true; 6: totally true)	
Activity monitoring	1	*Did you have to wear the activity monitoring device today?* (yes/no) -> if no: end of diary -> if yes: a tool is provided in which participants can indicate when they started to wear the device, when they took it off and the reason for taking it off. This gives an idea on the (non-)wear time at a daily basis.	

Table 5: Constructs, Number of Items, and Item + Scales of the Parent Diary

Construct	# **items**	**Item + Scale**	**Source**
Parental Mood	10	Positive: *Alert, Inspired, Determined, Attentive, Active* Negative: *Upset, Hostile, Ashamed, Nervous, Afraid*	Positive and Negative affect Schedule / International Panas Shor Form (10-item; Thompson, 2007; Watson, 1998)
Child General Functioning	6	- *Please indicate which activities your child planned to do today?* *Activities that have something to do with…* (multiple choice item; options: I don't know this, school, friends, family, hobby's, sport, household chores, others (*space to*	

		provide details). - *Did your child do less or more than the activities that he/she had planned?* (-3: far less activities, 0: did what I planned to do; +3: far more activities) - *My child had difficulties with doing activities today* (0: not at all true; 6: totally true)	
Child School Attendance	1	*Did your child attend a full day (or a half day on Wednesday) of school today?* (yes/no) (<u>conditional item</u>) -> if yes: continue -> if no: *Why did your child not attend a full day of school?* (<u>option 1:</u> There was no school because it is a holiday or weekend; <u>option 2:</u> My child did not attend school because of the pain or other physical complaints; <u>option 3:</u> other (*option to provide details*)	
Child Pain Intensity	2	- *How intense do you think your child's pain was on average today?* (0: no pain; 6: worst possible pain) - *How intense do you think was your child's worst*	Graded Chronic Pain Scale for Children (Von Korff, 1992; Dutch version, Vervoort, 2014) – two items of the *characteristic pain intensity subscale*

		pain today? (0: no pain; 6: worst possible pain)	
Child Physical Complaints	1	*Did your child experience other physical complaints today?* (0: no complaints; 6: a lot of other complaints) (<u>conditional item</u>) -> if no: continue -> if yes: *If yes, which other physical complaints* (space provided to give details)	
Child Medication Use	1	*Did your child take pain medication today?* (yes/no)	
Child Pain Behaviour (Overt)	2	*When my child experienced pain or other physical complaints today…* *- he/she overtly showed that he/she experienced pain or other physical complaints (e.g., painful expressions, cry or complain, walking slowly or cautious because of the pain)* * *- talked to me about his/her feelings concerning the pain or other physical complaints* * (0: not at all true; 6: totally true)	Based on Pain Behavior Checklist (parent report items are based on partner report items (D. Kerns, vertaald door L. Goubert, P. Marquebreuck en M. Marquebreuck, 2008.) (back-translation procedure)
Child Pain	1	*Today, my child had*	Based on pain interference

Interference		*difficulties with doing my activities because of the pain or other physical complaints* (0: not at all true; 6: totally true)*	items (Graded Chronic Pain Scale - *disability* subscale)
Child Activity-Engagement	1	-*Today, my child did his/her planned activities while he/she was in pain or had other physical complaints* (0: not at all true; 6: totally true)* - *Today, it was important for my child to (at least try) to do his/her activities while he/she was in pain or had other physical complaints* (0: not at all true; 6: totally true)* - *Today, my child did his/her best to do the activities that he/she finds important or fun to do while he/she was in pain or had other physical complaints* (0: not at all true; 6: totally true)* * <u>conditional items</u> on items about pain and physical complaints. Not shown when parent reported no pain AND no physical complaints.	*CPAQ – activity engagement* subscale (adjusted to parent report; McCracken et al., 2010)
Child Avoidance of	3	- *Today, my child skipped*	*Fear of Pain Questionnaire –*

activities		*activities because he/she thought the pain or other physical complaints would worsen by doing so* (0: not at all true; 6: totally true) - *Today, my child stopped with what he/she was doing because the pain or other physical complaints started or became worse* (0: not at all true; 6: totally true) - *Today, my child took some rest instead of doing activities because of (potential) pain or other physical complaints* (0: not at all true; 6: totally true)	Avoidance subscale (adjusted to parent report item; Simons et al., 2011)
Parent Catastrophizing (about child pain)	3	- *Today, I thought something serious might happen to my child because of the pain* (0: not at all true; 6: totally true) - *Today, I kept thinking about how much pain my child was experiencing* (0: not at all true; 6: totally true) - *Today, I felt I couldn't go on much longer because of my child's pain* (0: not at all true; 6: totally true)	Pain Catastrophizing State Items (Durand et al., 2017; adjusted to parent report)
Parent Pain-Related Fear (of child pain)	1	- *Today, my child's pain caused my heart to beat fast*	Fear of Pain Questionnaire; *fear of pain subscale* (Simons

		or race (0: not at all true; 6: totally true) - *Today, my child's feelings of pain were scary for me* (0: not at all true; 6: totally true) - *Today, I worried about my child's pain* (0: not at all true; 6: totally true)	et al., 2011) (adjusted to parent report)
Parent instructions (avoid-accept)	2	- *Today, I told my child to stop or cancel activities because of the pain or other physical complaints* (0: not at all true; 6: totally true) - *Today, I told my child today to keep on doing fun or important activities (or any other activities he/she usually does) while he/she was in pain or had other physical complaints.* (0: not at all true; 6: totally true)	*CPAQ – activity engagement* subscale (adjusted to parent instruction; McCracken et al., 2010) *Fear of Pain Questionnaire* – Avoidance subscale (adjusted to parent instruction; Simons et al., 2011)
Parent protective behavior	2	- *Today, I have made sure that my child did not have to do certain activities (e.g., household chores, going to school, or sports) because of the pain or other physical complaints.* (0: not at all true; 6: totally true) - *I cancelled my activities*	Inventory of parent/caregiver responses to child's pain (IRPEDNA; Huguet et al., 2008) – *solicitous behavior*

		(e.g., job-related duties, household chores, and/or hobbies) to be with me (0: not at all true; 6: totally true)	

Method 2: Objective Physical Activity Monitoring

At T0 (= before the surgery), T1 (= 3 weeks postoperatively) and T2 (= 6 weeks postoperatively) the adolescent was asked to wear an activity monitoring device (accelerometer) in order to get objective data from their daily physical activity. The type of activity monitoring device in this study was an Actigraph [56]. The ActiGraph [56] is an ambulatory activity-monitoring device that registers the adolescent's daily (and nightly) physical activity. This is a non-invasive device and can be worn around the waist at the right side of the body. It has a battery endurance of more than two weeks. The ActiGraph gives an objective and detailed report of the adolescent's physical daily (and nightly) activity [56]. And registers activity at an interval of 15 seconds. It classifies physical activity as light, moderate or vigorous activity.

Method 3: Questionnaires

All questionnaires were administered by means of an online web-based tool (i.e. LimeSurvey [58]). Parents and adolescents were asked to complete t on a computer at home after the diary registration week (see below) at each measuring point (T0-T4).

- *Socio-demographic questionnaire:* Socio-demographic data collected for this study include a) surgeon and center (Ghent, Bruges, Leuven or Antwerp) , b) age, c) gender, d) educational level, e) parents' marital status, f) adolescent's ethnic background, f) highest level of parent's education, and g) parent's occupation. In order to obtain this information both the adolescent and his/her parent were asked to complete a sociodemographic questionnaire (the adolescent was provided with a shorter version).
- *Biomedical Parameters:* Each surgeon (or assistant) was asked to complete a biomedical questionnaire providing pre-, peri- and postoperative medical details about the participant. They were asked to complete this in the time between 3-6 weeks after surgery.
    - Pre-operative data
        - BMI (length (cm); weight (kg))

- Curve Type (Location: Thoracic, Lumbar, Thoracolumbar; Direction: dextroscoliosis, levoscoliosis)
- Cobb Angle (degrees)
- Skeletal maturation (Risser Sign; Grade I (= least ossification and greater risk of progression) – Grade IV (= complete ossification and least risk of progression)
- Treatment history (observation/evaluation, physical therapy, breathing exercises, brace, prior surgery (scoliosis), other *(option to provide details)*
- Other medical and non-medical complaints:
    - Back pain (if yes: which treatment was applied (pain medication, physical therapy, others *(option to provide details)*, no treatment)
    - Breathing difficulties
    - Heart disease
    - Psychological problems *(option to provide details)*
    - Developmental disorder
    - Others *(option to provide details)*

- Peri-operative data:
    - Complications while at the hospital (yes/no)
        - If yes indicate (bleeding; lung problems; noxious after anesthesia; wound infection; movement of bars; hooks or screws; nerve damage; low hemoglobin; others *(option to provide details)*)
    - Treatment in the hospital
        - Department (pediatrics/adult)
        - Duration (1 week; 7-14 days; 14-21 days; 21-28 days; > 28 days)
        - Pain treatment (pain pump, morphine patches, paracetamol (dose, frequency, duration), others *(option to provide details)*)
        - Pain measurements (10-point response scale or other tools; frequency (<1x/day, 1x/day, 2x/day, 3x/day, >3x/day)
        - Other treatments (other medication (noxious/vomiting; anxiety; others *(option to provide details)*; mobilization (days of bedrest, start day, others *(option to provide details)*)
- Post-operative data
    - Complications at home (yes/no)

- If yes indicate (bleeding; lung problems; noxious after anesthesia; wound infection; movement of bars; hooks or screws; nerve damage; low hemoglobin; others *(option to provide details)*)

- Pain treatment (pain pump, morphine patches, paracetamol (dose, frequency, duration), others *(option to provide details)*)
- Other treatments (other medication (noxious/vomiting; anxiety; others *(option to provide details)*; mobilization (days of bedrest, start day, others *(option to provide details),* sport (number of months without any sport, swimming/riding the bike permitted start date, all sports permitted start date)

- <u>*Baseline adolescent psychosocial functioning measures:*</u>
  - *Vragenlijst voor Scoliosepatiënten (SRS-22r).* The SRS-22r [37] assesses the health-related quality of life in patients with idiopathic scoliosis. It is a self-report questionnaire that consists of 22 items that measure the patient's quality of life in 5 life domains: pain, self-image/self-esteem, functioning, mental health and satisfaction with self-management. Each item is rated on a five-point response scale. Example items are (in Dutch): "*Welke van de volgende mogelijkheden beschrijft het beste de hoeveelheid pijn die je gehad hebt in de afgelopen XX maand?"* and/or *"Hoe zou je je voelen als de vorm van je rug de rest van je leven blijft zoals die nu is?"* In this study we will only use the "self-image/self-esteem" subscale. The Dutch version has been validated in a one sample of patients with adolescent idiopathic scoliosis (mean age: 16) ,although the researchers acknowledge that further validation and reliability tests are necessary to fully validate the SRS-22(r) for children under 18 [36]. The English, Spanish, Turkish and Chinese versions have been validated with patients between 8-48 years [37]. For this study only the subscale measuring 'self-image' (five items) and two items measuring 'satisfaction with self-management' will be included, this scale consists of 5 items.
  - *Pediatric Health-Related Quality of Life* (PedsQL). The generic PedsQL (adolescent and parent report; [53,54]) will be used to assess the adolescent's health-related functioning/impairment in several domains before and after surgery. The PedsQL, parent and adolescent reports, assesses the health-related quality of

life by measuring physical, emotional, social, and school functioning of the adolescent. Items all begin with the stem, *"In the past one month, how much of a problem has this been for you/your adolescent…"* and response options range from 0, "Never" to 4, "Almost Always." Example items are "Paying attention in class," and "Getting along with other teens." Raw scores are transformed into standard scores on a 0-100 scale with higher score indicating better functioning (less impairment). Furthermore subscale scores can be calculated for Physical and Psychosocial Functioning.

- *Functional Disability Inventory (FDI).* The FDI [34;35] assesses adolescent's perceived difficulty in physical and psychosocial functioning that is due to physical health. The instrument consists of 15 items the adolescent's perceptions of their activity limitations during the past two weeks; total scores are computed by summing the items. Higher scores indicate greater disability. The FDI has been consistent found to have good reliability and validity.
- *Adolescent's and parent's self-reported expectancies (*9 items). The adolescent as well as his/her parent will be questioned about their expectations about the surgery and recovery process on several domains of functioning (pain, self-image, satisfaction, emotional, social). Based on a questionnaire that was used in a study with adolescent scoliosis patients [55] we will use a translation of the 9 items they used for measuring parent and patient's expectancies about the surgery. These items are translated in Dutch by the researchers in this study via back-translation.

o <u>*Baseline adolescent physical activity measures*</u>:

- *Flemish Physical Activity Questionnaire (FPAQ – child (8-12) and adolescent (12-18) version).* The FPAQ [30] assesses the child/adolescent's physical (in)activity of a usual week in several domains: school-related activity, transportation ways/time (school and leisure times), sport participation in leisure time, and sedentary activities (e.g. watching television, playing computr games). A total physical (in)activity score (in hours/week) can be calculated, as well as different subscale scores for each of the abovementioned domains (minutes/week). The reliability and validity of the FPAQ (adolescent version) have been showed in a study with 33 Flemish adolescents between 12-18 years old [30]. An adapted version for primary schoolchildren (9-12 years old) showed medium to good psychometric qualities in one study with 43 schoolchildren, better qualities were shown if children were helped by their parents in completing the questionnaire [31].

- <u>*Baseline adolescent pain measures:*</u>
  - *Graded Chronic Pain Scale (GCPS; adolescent report).* The GCPS [32] is a (self-report) questionnaire that consists of 8 items that measure adolescent chronic pain severity. Scores can be obtained on two subscales measuring 'pain intensity' and 'pain disability' during the past 6 months. The GCPS also assesses the type of chronic pain condition. In this study we will use an adapted 8-item version of the GCPS (adolescent and parent report) [33]. Both the GCPS and the adapted version have been validated in pediatric samples. This measure will be used to assess adolescent's pain (intensity and disability) at each moment in time after the surgery. This measure will also give more information about the persistence of the post-operative pain (going from acute to chronic).
- <u>*Baseline psychosocial risk and resilience factors (adolescent and parent):*</u>
  - *Parent and Adolescent Pain Catastrophizing Scale (PCS-P; PCS-C).* The PCS-C [46] assesses the adolescent's negative thinking associated with pain. It consists of 13 items, which adolescents rate on a 5-point scale. It yields a total score and three subscales scores: "Rumination", "Magnification", and "Helplessness". The internal consistency of this measure is 0.90. Similarly, the PCS-P [25] measures catastrophic thinking about child pain in parents. Good psychometric properties have been shown in a sample of parents of schoolchildren [59].
  - *Parent and Adolescent Positive and Negative Affect Scale (PANAS; PANAS-C).* The PANAS-C [38] and PANAS [39] are self-report measures of positive and negative affect. The questionnaire consists of 30 (resp. 20) items that all describe a positive or negative emotion or feeling. The adolescent/parent will be asked to rate each item on a five-point scale indicating to what extent they generally felt that way (during the past weeks). Separate scores can be obtained for the subscales 'positive affect' and 'negative affect'.
  - *Parent and Adolescent Life Orientation Test (YLOT; LOT-R).* The LOT ([40,42]; Dutch version [41]) and the Y-LOT [43] assess the extent to which individuals generally expect favorable outcomes. The (Y-)LOT consists of 12 statements: 4 are positively stated, 4 are negatively stated, and 4 are filler items. Participants are asked to rate each statement on a five-point response scale ('0', strongly disagree; '4',strongly agree). A total score can be obtained with higher scores reflecting higher

levels of general optimism about the future. The LOT and YLOT have both been validated in samples of adults and adolescents.

- *Adolescent Avoidance and Fusion Questionnaire (AFQ-Y).* The AFQ-Y [45] is a self-report questionnaire that measures the degree of psychological flexibility in the adolescent/adolescent. It consists of 17 items that measure three basic processes underlying psychological flexibility: (1) Cognitive fusion (e.g., "My thoughts and feelings mess up my life," "The bad things I think about myself must be true"); (2) Experiential avoidance (e.g., "I push away thoughts and feelings that I don't like"); and (3) Inaction or behavioral ineffectiveness in the presence of unwanted internal experiences (e.g., "I can't be a good friend when I feel upset"). The adolescent/adolescent will be asked to rate how much each item is true for him/her on a five-point response scale ("0", not at all true; "4", very true). Good psychometric properties of the AFQ-Y were shown in a sample of children/adolescents.
- *Children's and Adolescent's Mindfulness Measure (CAMM-NL).* The CAMM [62] measures mindfulness skills in children and adolescents. The CAMM consists of 10 statements which are formulated in terms of the absence of mindfulness. Each item is scored on a scale from A total score can be obtained (0-40), with lower scores indicating higher tendencies to be mindful in everyday life. The CAMM has been validated in (non-clinical) samples of school-aged children and adolescents [62,64]. In this study a Dutch translation by de Bruin (2010) will be used, which has been shown to have good psychometric properties in a sample of children and adolescents [65].
- *Willingness and Action Measure (WAM-A/C)* [70,71]. The WAM aims tom measure experiential acceptance in adolescents (9-17 years). The item of the WAM-C/A can be divided onto two subscales: ´willingness´ and ´action´. The willingness scale consist of five items. An example item is: *´It's OK to have thoughts that make me feel sad or scared´*. The action scale consists of nine items with *´I stick to things that matter to me, even when I feel sad or scared´* as an example item. Each item has to be rated on a five point response scale ('1', not at all true; '5', very true). A higher total score indicates higher acceptance. The English version of the WAM-C/A has shown to have good internal consistency, with alphas ranging from .88 to .91 [70]. However, the Dutch version has, to our knowledge, only been validated in one study yet and showed moderate internal consistency reliability [71].

- *Pediatric PROMIS items: Depressive Symptoms (SF-8b) + Peer Relations (SF-8a)* [68,69]. These items are token from a large and internationally used item bank (i.e. PROMIS item bank). The short form 'Depressive Symptoms' consists of 8 items that question the adolescent's depressive feelings during the last week. Example items are: '*Ik voelde me alleen' of 'Ik voelde me verdrietig'.* The short form 'Peer relations' also consists of 8 items measuring the adolescent's peer relations. Example items are: '*Mijn vrienden en vriendinnen en ik hielpen elkaar'* of '*Andere kinderen wilden met me praten'.* Adolescents are asked to rate these items on a five-point respons scale ('0', never; '4', almost always). The Dutch PROMIS-item banks are currently being validated in different populations.
- *Acceptance and Action Questionnaire (AAQ-II; parents).* The AAQ-II [60;61] assesses experiential avoidance, or its opposite: psychological flexibility. In this study the 7-item AAQ-II will be used, since this recently showed to be psychometrically stronger than the 10-item version. Furthermore it has been showed that the Dutch version is a psychometrically strong instrument for both adults and adolescents.
- *Parental Acceptance Questionnaire (6-PAQ).* The 6-PAQ [49; translated in Dutch through back-translation procedure by Melanie Beeckman et.al. (approved by author)] measures psychological flexibility in parents across the six representative ACT (Acceptance and Commitment Therapy) processes (i.e. acceptance, defusion, being present, self as context, values and committed action). The 6-PAQ consists of 18 items asking the parent about its interaction with and feelings about (parenting) their adolescent. A total score and six subscale scores (i.e. for the six ACT-processes) can be obtained. Preliminary validations shows it to be a reliable and valid measure in sample of parents of schoolchildren.
- *Parenting Dimensions: Responsivity, Autonomy Support and Psychological Control [47,51,52].* These three important dimensions of parenting style will be measured by a Dutch questionnaire composed of several items from other scales measuring these dimensions separately. Parental responsivity will be measured by 7 items, these have been validated in several studies [47]. Psychological control in parents will be measured by 8 items which also have showed to have good psychometric properties [51]. Finally, parental autonomy support will be measured by 7 items which have been validated in several studies [52].

- *Overprotection Scale – Anxiety-driven parenting, Premature Problem Solving and Babying*. The OPS [66] measures overprotective parenting behavior. This is a relatively new scale which is constructed to assess overprotective parenting in parents of normal developing children. The total scale encompasses five subscales, but for the purposes and aims of this study only three scales will be used (the Dutch construct names are given): 'Angstig opvoeden', 'Voortijdige probleemoplossing' and 'Babying'. Each scales consists of five items and each item has to be rated by either the child or the parent (i.e. depending on the version) on a five-point response scale (from '1',not at all true to '5', totally true). Example items are: "Mijn moeder waarschuwt me voortdurend voor dingen die me zouden kunnen overkomen." (Angstig opvoeden); "Mijn moeder komt dikwijls tussen bij dingen die ik eigenlijk zelf zou kunnen oplossen" (Voortijdige Probleemoplossing) or "Mijn moeder zou willen dat ik onder haar vleugels bleef" (Babying). Statements for either the father or the adolescents are formulated in the same way. Good psychometric properties of this scale have been shown in several studies with healthy school-aged children and adolescents (i.e. as a part of master theses), none of these studies have, however, been published yet [66].
- *Inventory of parent/caregiver responses to adolescent's pain experience* (IRPEDNA, parent report). The IRPEDNA [57] measures parent's reactions to their adolescent in pain on three dimensions: "Solicitousness", "Discouragement" and "Promotion of well-behaviors and coping". In the IRPEDNA, parents are asked to rate their own responses to their adolescent's pain on 37 items. Each item is rated on a 5-point scale referring to the frequency of responding in the way that is stated in the particular item. A good internal consistency and validity of the IRPEDNA was shown in a sample of parents of school-aged adolescents.
- *Adolescent Chronic Pain Acceptance Questionnaire (CPAQ-A).* The CPAQ-A [44] is a self-report questionnaire that measures the degree acceptance of pain in children/adolescents. The questionnaire consists of 20 items which can be divided onto two subscales, measuring the adolescent's engagement in daily life activities despite the pain and its willingness to experience pain. Each item has to be rated on a seven-point response scale ("0", never true; "6", always true). The CPAQ-A has been validated in a sample of adolescents with chronic pain.

○ *Follow-up/Post-operative measures*

- *Parental Psychological Flexibility Questionnaire (PPFQ).* The PPFQ [48] measures psychological flexibility in parents in the context of their adolescent's pain. It consist of 31 items that can be divided onto three subscales: "Acceptance", "Cognitive Defusion" and "Committed Action". The parent is asked to rate the personal applicability of each statement on a seven-point response scale, ranging from 0 ('never true') to 6 ('always true'). Sample items are "*When my adolescent has pain episodes I am able to realize at the time that it will pass"* (i.e. positively reflecting psychological flexibility) and "*I suffer terribly from my adolescent's pain and need to make the suffering stop"* (i.e. negatively reflecting psychological flexibility). A Total Score (0-186) can be obtained with higher scores indicating more parental psychological flexibility in dealing with their adolescent's pain. Good psychometric properties of the PPFQ were shown in a sample of parents from adolescents with chronic pain.
- *Parental Pain Acceptance Questionnaire (PPAQ).* The PPAQ [50] is a 15-item tool to assess parents' acceptance and responses in the context of adolescent pain. The measure consists of two subscales for which scores can be calculated: 'Activity Engagement' and 'Pain-related Thoughts and Feelings'. In this study a Dutch translation of the items will be used, which is based on the validated Dutch items of the child version and the adult version of the chronic pain acceptance questionnaire. The English version of this questionnaire has been validated in one study with parents of youth with chronic pain in an outpatient treatment program [50].
- *Vragenlijst voor Scoliosepatiënten (SRS-24 – postoperative items).* At 1 year the adolescent will be asked to complete 7 items questioning the patient's evaluation about his/her treatment and related changes on several domains: physical activity, social relations, self-image and back pain. In this study we will use a back-translated Dutch version of the English items. These items were also used in another postoperative follow-up study with adolescents with idiopathic scoliosis [2].

II. **Data Management**

All questionnaire data collected for the study will be entered into SPSS. All data will be anonymized and only the responsible researcher of Ghent University will be able to link the data to the participants. It will never be possible for any other person than the researcher to identify participants who took part in this study. Data will be maintained in the

Limesurvey [58] server and on password-protected files/shares on the server Ghent University. Data will be maintained in private, non-shared, protected folders stored on central server of Ghent University. The university system (i.e. DICT) provides nightly backup of files stored on its server. All hard copies of questionnaires and interviews will be stored separate from consent forms or other documentation containing identifying information (which will also be stored in locked files). Only approved research staff will have access to these files. Identifying information will not be entered or stored on the computer with the behavioral data; thus, all relevant data other than separated consent forms will be de-identified.

III. Statistical Methods

- **Measurement burst design.** Data will be collected at five points in time: immediately before the surgery (T0), 3 weeks after surgery (T1), 6 weeks after surgery (T2), 6 months after surgery (T3) and 12 months after surgery (T4). At each point in time both daily diary and activity data will be collected, as well as questionnaire data. The design for this kind of longitudinal study is called a *measurement burst design*, which can be described as follows: *"The measurement burst design is a design that incorporates bursts of intensive repeated assessment within a relatively short period of time (e.g., days, weeks) that are repeated longitudinally, over more widely spaced temporal intervals (e.g., annually). This design lends itself to the study of short-term variability, long-term change, and individual differences therein. Further, the measurement burst design facilitates the study of dynamic processes that transpire over different temporal scales and how these processes influence one another.* (abstract [67])*"*. This design gives us the possibility to meet this study's aims and answer examine adolescent's within-person variability in (pain-related) behavior at each measuring point and long-term change in behavior and functioning indicating the evolution in recovery. Furthermore this design also lends to the study of between-person differences in postoperative recovery processes and change general functioning and possible variables predicting these differences.
- **Preliminary analyses**. These analyses will be done to test the underlying assumptions of each statistical procedure (e.g., normal distribution). Bivariate correlation analyses will be conducted to examine relationships among the variables. Any demographic or other descriptive variables (e.g. sociodemographic variables such as pain diagnostic group, adolescent age, adolescent gender,…) that correlate with the outcome variables of interest will be included as covariates in further regression analyses. We will examine

the psychometric properties (e.g. internal reliability) of the measures used in the study to confirm whether they operated as expected in our sample.

- **Hypothesis testing.** The longitudinal data will be analyzed through structural equation modelling (SEM) in MPLUS and multilevel analyses for the diary data. More details about the specific analyses will be provided in the different papers that will be written to report on these data.

C. DATA MONITORING

I. **Data Monitoring**

All data is stored on internal servers of Ghent University. In an effort to limit the potential bias introduced to the study due to discrepancies in access to computers and the internet, participants may elect to complete questionnaires and/or the diary on paper. If participants prefer this option, a research team member has e-mailed the packet questionnaires to the family. This packet also included a stamped self-addressed envelope for returning the questionnaires to the research assistant.

II. **Harm**

No specific harms were expected as a consequences of participating in this study. Wearing the activity monitoring device has been shown to be not invasive or harmful [56]. However, participants were given the possibility to take the device off when it caused discomfort and make note of this in the daily diary. The daily diary might cause some feelings or thoughts about the pain or physical health to be more elicited than would have happened without the diary. However, it is not expected that these items will cause psychological problems. However, at the end of the diary a message of the researchers was included to motivate participants who did experience the diary as unpleasant to talk to someone about this (e.g., parents, physician, psychologists). The researchers also mentioned that they could be contacted and refer the adolescent/parent to professional help if needed. All adolescents were informed that they could stop their participation in the study at any time without any further consequences for the study or their treatment at the hospital. Participants were not requested to give a reason for their withdrawal.

D.ETHICS AND DISSEMENATION

I. **Research Ethics Approval**

This protocol has been approved by the Commission for Medical Ethics of the University Hospital of Ghent (central committee) and the local ethical committees of AZ Brugge, UZ Antwerpen, & UZ Leuven. The reference number is BC-2016/0818 (BUN: B670201629014/I/U) The committee has approved that data can be collected until December 31st, 2018. A maximum of 120 participants can be recruited for this study.

II. **Protocol Amendments**

All amendments have been/will be submitted to the central ethical committee of UZ Gent. Following amendments have been made and were approved:

- 23/11/2016 – addition of study site (UZ Leuven)
- 27/01/2017 – maximal age of participants changed from 15 to 18 years
- 17/03/2017 – notification of new research team members (UZ Leuven; Orthopedic Research Team)

III. **Consent**

At the start of the study the adolescent and their parents were asked to sign an informed assent/consent. All adolescents were under-aged, therefore they needed informed consent of (one of their) parent(s) for their participation in this study. Parents were also asked to give their informed consent for their own participation. Adolescent participants were also asked to give their informed assent for their own participation. Informed consent/assent was retrieved via a question in the first diary of the first diary registration week.

IV. **Confidentiality**

All e-mail correspondence was primarily conducted via the parent (with the adolescent added to the mailing list if preferred). We have used a password-protected link to access the surveys (diary and questionnaires) as a way to authenticate the identity of the participant responding to the survey. Parent and adolescent participants received a separate link and a personal code to access their own daily diary/questionnaires.

The personal codes were used as a way to anonymize the collected data. These codes were designed in such a way that adolescent and parent data could be linked afterwards. The key providing the link between the personal codes and the personal information (names, contact

details) is only accessible to the principal investigator. Personal data and collected data for the study were saved separately.

Participants were informed about the relative security of different types of e-mail accounts and asked to provide a secure e-mail address to the member of the research team.

V. Declaration of Interest

The principal investigators have no conflicts of interest to declare.

VI. Access to Data

Only the principal investigator has access to the final data set. All data (diary, questionnaire, actigraph) are saved by means of personal codes. Personal data are saved in a separate file. The principal investigator has the key to link the personal data to the data that has been collected for this study. This will be saved in a password-protected file.

VII. Dissemination Policy

Different papers will be written to report on the various aims and objectives of this large scale longitudinal study To define the authorship of the publications, the contributions of the multiple participating hospitals will be taken into account. For this we will rely on the recommendations for the conduct, reporting, editing and publication of scholarly work in medical journals, formulated by the ICMJE (International Committee for Medical Journal Editors, http://www.icmje.org).

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