

Atelier n°8: Les prises en charges alternatives de la douleur

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Sources de douleur dans la mucoviscidose

■ Douleur Physique

- Douleurs thoraciques:
 - ✓ Exacerbation respiratoire, séance de kinésithérapie (28% des enfants, 10% des adultes)
 - ✓ Pneumothorax
- Douleurs sinusiennes
- Douleurs abdominales
 - ✓ SOID
 - ✓ Pancréatite
 - ✓ Constipation chronique
- Douleurs liées aux gestes invasifs:
 - ✓ Gaz du sang
 - ✓ Perfusions: périphériques, PICC, Port à Cath...
- Douleurs articulaires
- Douleurs musculaires

Ayers S et al. British Journal of Health Psychology, 2011

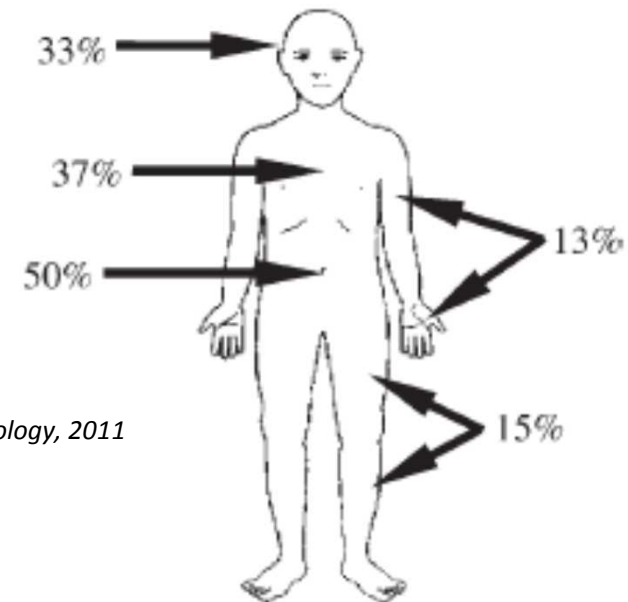


Fig. 1. Proportion of patients reporting pain in each body region.

Koh J et al. Ped Pulmonol 2005

■ Douleur Morale

- Traumatismes répétés
- Anxiété liée à la douleur physique et au pronostic
- Dépression

Enjeux de la prise en charge de la douleur

- Symptôme précoce et fréquent
 - Prévalence de l'ordre de 50 à 80% selon les études

Blackwell L et al, Ped Pulmonol 2015, Festini F et al Journal of Cystic Fibrosis 2004, Sermet-Gaudelus I et al. J of Pain and Symptom management 2009, Koh J et al, Ped pulmonol 2005, Abbott L et al, AJRCCM 2009



Enjeux de la prise en charge de la douleur

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- Adhérence / Observance

TABLE 4— Multiple Regression Analysis of the Relationship Between Pain Intensity and Pulmonary Adherence, Depression, and Anxiety

Characteristic	B	SE (B)	β	t	Sig. (P)
Anxiety	0.036	0.060	0.090	0.597	0.553
Depression	0.176	0.069	0.389	2.563	0.013

TABLE 5— Multiple Regression Analysis of the Relationship Between Average Change in Pain Intensity and Pulmonary Adherence, Depression, and Anxiety

Characteristic	B	SE(B)	β	t	Sig. (P)
Anxiety	0.111	0.049	0.362	2.249	0.029
Depression	0.036	0.053	0.112	0.688	0.495

Blackwell L et al. Ped Pulmonol 2015

Enjeux de la prise en charge de la douleur

Author	Rationale	Sample	Pain assessment/time frame	Results (frequency, pain location, treatment/self-management, impact on daily life/HRQoL)
Ravilly et al., 1996 [7]	Examine clinical pain management in relatively sick patients	78 adults 58 deceased, mean age at death = 26 23 alive, mean age 23 Mean FEV ₁ = 58%	Chart review February 1986–October 1993	Frequency: All charts showed that patients reported pain, 84% reported serious pain, especially towards death. Locations: chest, headache, back, limb, abdomen. Management: >50% tried non pharmacological approach (acupuncture, TENS, biofeedback); medications: NSAID, tricyclic antidepressants, thoracic epidural analgesia, opioids. Patients attended a pain treatment centre. Impact: not recorded
Epker et al., 1999 [8]	Assessment of pain and pain related impairment in adults with Cystic Fibrosis	75 adults	MPI Time frame not specified	Frequency: 69% reported pain severity of 2 or less, 24% reported no pain. Locations: not recorded. Management: not recorded. Impact: 63% pain-related interference of 2 or less, 17,3% no interference; 38,7% reported an affective distress score of 2 or less and 61,3% reported a score of 3 or less. 60% reported a life control score of 4 or more and 25,3% reported general activities of 4 or greater.
Festini et al., 2004 [9]	Evaluate prevalence of pain, self-management and impact on everyday life	239 adults Mean age = 26 Mean FEV ₁ = 56%	Ad hoc questionnaire Past 2 months	Frequency: 225/239 reported pain. Location: headache, stomach, heartburn, backache, bones/muscular pain, abdominal, chest. Management: 24% homeopathic or non-pharmacologic remedies; 91% took medicine, not specified. Impact: 63% unfavourable impact on daily activity.
Koh et al., 2005 [11]	Assessment of acute and chronic pain and pain management and the relationship of pain with disease severity	46 children and adolescents Mean age 12.9 Mean FEV ₁ = 80%	Faces Pain scale Body outline VAS Retrospective over 1 month	Frequency: 46% reported pain at least once a week. Majority reported mild procedural pain. Location: abdominal/pelvic, chest, head/neck. Management: rest, relaxation, heat or cold, family/friends, distracting; medication: acetaminophen, NSAID. Impact: children with chest pain were at risk for experiencing functional limitations and lower FEV ₁ %.
Palermo et al., 2006 [12]	Assessment of pain and impact on HRQoL	46 children and adolescents Mean age 12.9 Mean FEV ₁ = 80%	Faces Pain scale Body outline VAS Retrospective over 1 month	Frequency: 46% experienced pain at least once a week. Location: abdominal/pelvic, chest, head/neck. Management: not recorded. Impact: pain was associated with decrements in HRQoL across multiple domains.
Sermet-Gaudelus et al., 2009 [13]	Assessment of pain prevalence, symptoms and treatment. Evaluation of the relationship between pain, disease severity and HRQoL	73 children, Mean age 10.2 Mean FEV ₁ = 70% 110 adults Mean age 28.5 Mean FEV ₁ = 50%	Ad hoc questionnaire Body outline drawings Retrospective over 1 month	Frequency: 59 % of children and 89% of adults reported at least one episode of pain. 85% and 78% reported procedural pain and anticipatory pain, more frequent in severe disease. Location: head, chest, abdominal (children > adults), backache (adult > children), muscular ache (child > adult). Management: 40% of children and 50% of adults reported use of analgesics: acetaminophen, NSAID, aspirin, antispasmodic treatments, opioids. Impact: 50% of children and 70% of adults reported intense, long-lasting and recurrent pain episodes that impacted their QoL.

Author	Rationale	Sample	Pain assessment/time frame	Results (frequency, pain location, treatment/self-management, impact on daily life/HRQoL)
Flume et al., 2009 [14]	Association between pain and sleep quality	50 adults Mean age 31 Mean FEV ₁ = 58%	Brief Pain Inventory Pittsburgh Sleep Quality Index Retrospective over 1 month	Frequency: 64% reported pain within last month. Location: abdomen, back, chest, extremities, head and neck. Management: not recorded. Impact: Pain is strongly correlated with
Stenases et al., 2009 [16]	To assess self-management of pain, dyspnoea and cough	64 children and 59 adults, Mean age 20 years	Ad hoc questionnaire Retrospective over 1 month	Frequency: 84% reported pain. Location: headache and abdominal pain. Management: non-pharmacological (resting, doing nothing, heat, cold); medication: acetaminophen, NSAID, aspirin, antispasmodic treatments, opioids. Impact: pain inhibited daily activity especially with increasing severity of pain.
Hayes, 2011 [4]	To assess the factors associated with pain and its impact on clinical outcome	83 patients Median age 29 Median FEV ₁ = 64%	Brief Pain Inventory Online Survey Retrospective over 1 month	Frequency: 82% reported moderate to severe pain. Location: head, sinuses, back, chest, abdomen, joints. Management: not recorded Impact: pain is associated low mood, poor HRQoL, pulmonary exacerbations and death.
Mursak et al., 2011 [17]	Prevalence of recurrent abdominal pain its management and impact on HRQoL	8 children Mean age 14 Mean FEV ₁ = 85%	Faces Pain scale Eland pain location Ad hoc questionnaire 28 daily pain diary	Pain catastrophizing correlated with increasing pain. Frequency: 8/130 patients fulfilled criteria for recurrent abdominal pain. Location: abdominal pain. Management: behavioural interventions and increasing pancreatic enzymes. Impact: pain according to criteria has strong impact on daily life.

FEV₁ = Forced Expiratory Volume 1st second; MPI = Multidimensional Pain Inventory; TENS = Transcutaneous Electrical Nerve Stimulation; NSAID = nonsteroidal anti-inflammatory medications; VAS = Visual Analogue Scale; HRQoL = Health Related Quality of Life.

Enjeux de la prise en charge de la douleur

■ Symptôme fréquent

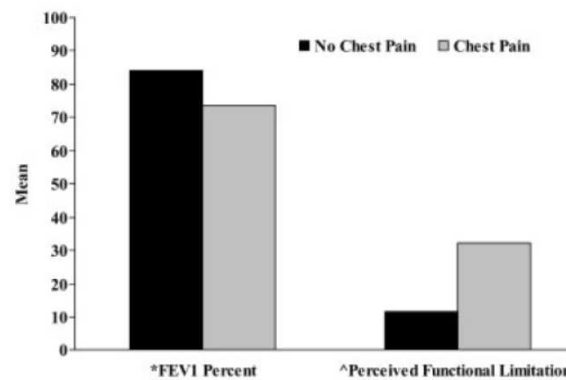
- Prévalence de l'ordre de 50 à 80% selon les études

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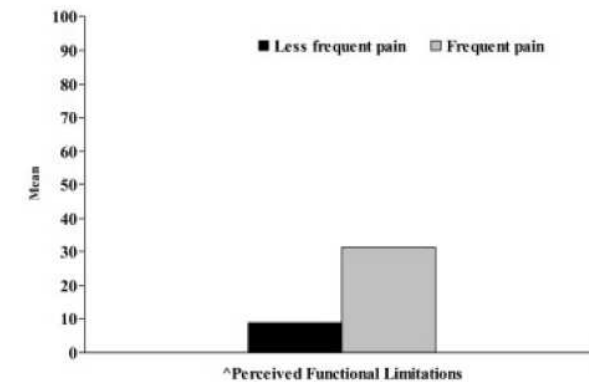
Blackwell L et al. Ped Pulmonol 2015, Hubbard et al. 2005, Lee A et al. J of Cystic Fibrosis, 2009, Kelemen et al. 2011

■ Sévérité / Survie



*p = 0.07
^p < 0.0001

Fig. 2. Effect of chest pain on disease severity and functional limitations.



^p < 0.0001

Fig. 3. Effect of frequent pain on functional limitations.

Koh J et al. Ped Pulmonol 2005

Enjeux de la prise en charge de la douleur

- Symptôme fréquent

- Prévalence de l'ordre de 50 à 80% selon les études

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- Sévérité / Survie

TABLE 3. ESTIMATE OF HAZARD RATIO FOR HRQOL DOMAINS
Estimate*

HRQoL Domain	HR (95% CI)	P Value
CFQoL		
Physical functioning	0.97 (0.96 to 0.99)	<0.001
Social functioning	0.99 (0.98 to 1.00)	0.239
Treatment issues	0.99 (0.98 to 1.00)	0.165
Chest symptoms	0.98 (0.97 to 0.99)	0.005
Emotional responses	0.98 (0.97 to 1.00)	0.032
Body image	1.00 (0.99 to 1.01)	0.916
Relationships	1.00 (0.99 to 1.01)	0.992
Career issues	1.00 (0.98 to 1.01)	0.401
Future concerns	1.00 (0.98 to 1.01)	0.665
SF36		
Physical function	0.99 (0.98 to 1.00)	0.069
Role limitation physical	0.99 (0.98 to 1.00)	0.172
Social function	0.99 (0.98 to 1.00)	0.115
Mental health	1.00 (0.98 to 1.01)	0.601
Role limitation mental	0.99 (0.98 to 1.00)	0.103
Pain	0.98 (0.97 to 0.99)	<0.001
Energy and vitality	0.99 (0.98 to 1.00)	0.112
Changes in health over the last 12 mo	0.98 (0.97 to 0.99)	0.002
General health perceptions	0.99 (0.98 to 1.01)	0.253

Definition of abbreviations: CFQoL = cystic fibrosis quality of life; CI = confidence interval; HR = hazards ratio; HRQoL = health-related quality of life; SF-36 = Short Form-36.

* Model including one HRQoL variable at a time. All models include the block of nine demographic and clinical variables.

Abbott J et al. AJRCCM 2009



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Hubbard et al., 2005 [10]	Investigate pain experiences, disability and coping strategies	18 adults (12 female) 67 % older than 23 years of age	Web-based questionnaire Retrospective over 1 month	Frequency: 17/18 reported pain. Location: chest, joints. Management: preferred coping style is active and accommodative (problem solving, resting, distraction). Impact: pain affected recreation, occupation, family/home responsibility, sex behaviour, self-care.
Koh et al., 2005 [11]	Assessment of acute and chronic pain and pain management and the relationship of pain with disease severity	46 children and adolescents Mean age 12.9 Mean FEV ₁ = 80%	Faces Pain scale Body outline VAS Retrospective over 1 month	Frequency: 46% reported pain at least once a week. Majority reported mild procedural pain. Location: abdominal/pelvic, chest, head/neck. Management: rest, relaxation, heat or cold, family/friends, distracting, medication: acetaminophen, NSAID. Impact: children with chest pain were at risk for experiencing functional limitations and lower FEV ₁ %.
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Lee et al., 2009 [15]	To assess a single musculoskeletal treatment session to alleviate pain and ease breathing	105 adults Mean age 30.5 Mean FEV ₁ = 48,1%	Body outline drawings Past 3 months	Frequency: 90% reported chronic pain. Location: musculoskeletal pain. Management: Improvement in ease of breathing was achieved using a combined approach of manual mobilization technique and massage therapy. Impact: pain impacts airway clearance and exercises.
Stenkes et al., 2009 [16]	To assess self-management of pain, dyspnoea and cough	64 children and 59 adults, Mean age 20 years	Ad hoc questionnaire Retrospective over 1 month	Frequency: 84% reported pain. Location: headache and abdominal pain. Management: non-pharmacological (resting, doing nothing, heat, cold); medication: acetaminophen, NSAID, aspirin, antispasmodic treatments, opioids. Impact: pain inhibited daily activity especially with increasing severity of pain.
[REDACTED]				
Kelmen et al., 2011 [3]	Prevalence, severity and location of pain. Psychosocial consequences and impact on HRQoL	73 adults Mean age 30 FEV ₁ = 60% Prospective study of 33 patients with acute exacerbation	Body outline drawing Brief Pain Inventory Previous week	Frequency: 89% reported pain. Location: head, neck, joints, chest. Management: not recorded. Impact: pain interfered with airway clearance for those with acute exacerbations and exercise interventions. Pain was related to poorer physical functioning, emotional status and greater interference with CF treatment, including exercise. Pain catastrophizing correlated with increasing pain.
Murck et al., 2011 [17]	Prevalence of recurrent abdominal pain its management and impact on HRQoL	8 children Mean age 14 Mean FEV ₁ = 85%	Faces Pain scale Eland pain location Ad hoc questionnaire 28 daily pain diary	Frequency: 8/130 patients fulfilled criteria for recurrent abdominal pain. Location: abdominal pain. Management: behavioural interventions and increasing pancreatic enzymes. Impact: pain according to criteria has strong impact on daily life.

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Pourquoi des prises en charges alternatives?

- Limitations des traitements pharmacologiques
 - Origines, localisations multiples
 - Peu ou mal prescrits, automédication
 - Effets secondaires, Contre-indications
 - Insuffisants et peu adaptés aux douleurs aiguës en rapport avec les soins

Sermet-Gaudelus et al. J of Pain and Symptom management 2009

- Complémentarité des prises en charges alternatives

- Mais... peu de données scientifiques validées

Quelles prises en charges alternatives?

- Contact humain, réassurance, information et implication du patient dans ses soins



Quelles prises en charges alternatives?

- Contact humain, réassurance, information et implication du patient dans ses soins
- Médecine personnalisée, consultation douleur Munck A et al. J of Cystic Fibrosis, 2012



Quelles prises en charges alternatives?

- Contact humain, réassurance, information et implication du patient dans ses soins

- Médecine personnalisée, consultation douleur *Munck A et al. J of Cystic Fibrosis, 2012*

- Kinésithérapie et massages *Lee A et al. J of Cystic Fibrosis, 2009*



Quelles prises en charges alternatives?

- Containants
- Médication
- Kinésithérapie
- Ostéopathie

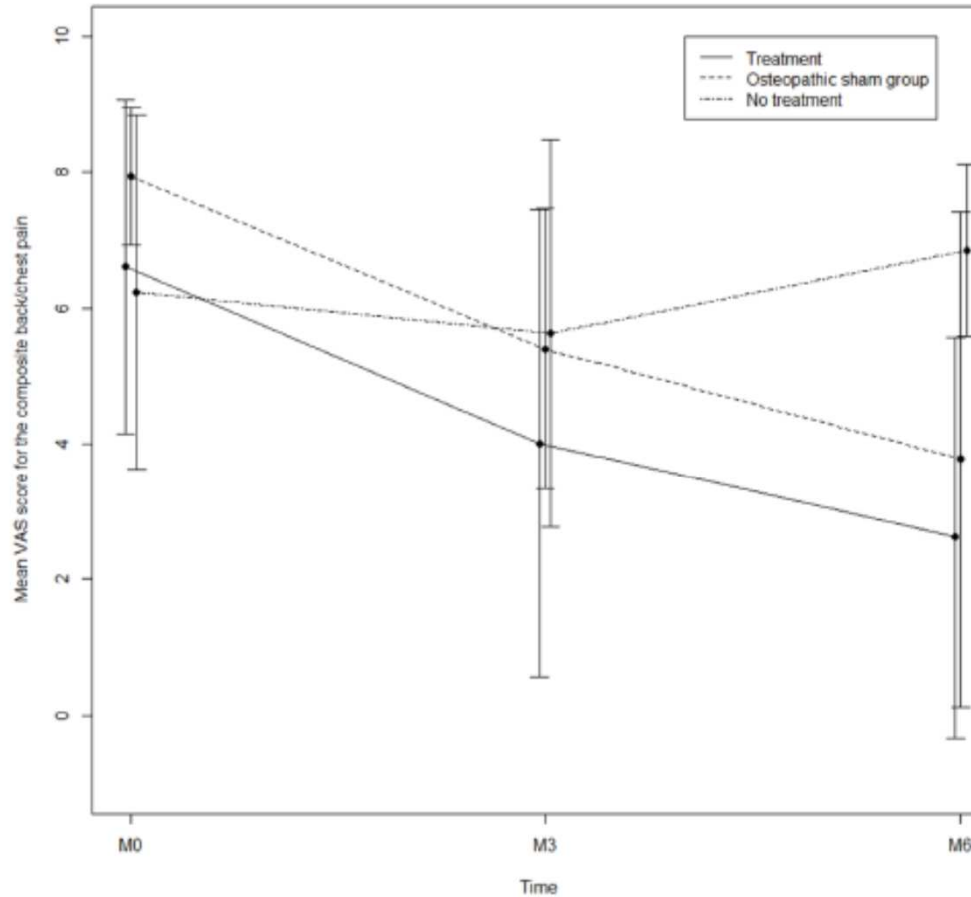


Figure 3. Composite chest/back pain at inclusion (M0), after 3 months (M3) and at the end of the study (M6) in the OMT group (A), the OMT sham group (B) and the group with only usual treatment (C). VAS: visual analog scale. doi:10.1371/journal.pone.0102465.g003

Hubert D et al. *J of Cystic Fibrosis*, 2014

u patient

ostic Fibrosis, 2012



Quelles prises en charges alternatives?

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- Ostéopathie *Hubert D et al. J of Cystic Fibrosis, 2014*
- Hypnose
-
-

L'hypnose et les soins difficiles



Hypnose: Définition

- C'est un mode de fonctionnement psychologique par lequel un sujet en relation avec un praticien, fait l'expérience d'un champ de conscience élargi.
- Deux dimensions
 - État modifié de conscience (transe, dissociation)
 - Relationnelle (communication inter subjectivité, activation d'un circuit de détente en même temps qu'une hyper attention)

Pierre Rainville 2004

Etat d'hypnose : être à la fois ici et ailleurs, dans deux réalités en même temps.

Hypnose: Présentation de la démarche

- Du Meopa à l'hypnose
Réflexion personnelle



Hypnose: Les freins

- L'âge
- Les résistances
- Les Parasites



Sensibilité hypnotique

Morgan et Hilgard 1973

- 0-6 ans distraction
- 7-9 ans réceptivité plus importante
- 9-12 ans très grande réceptivité
- Ados hypnotisabilité constante doit être actif
- Adultes difficultés vers 40 ans demande plus de travail
- P agés demandent des ajustements, proximité physique, Capacités d'attention ↘



Les personnes les plus faciles sont « les enfants rêveurs, les grands voyageurs »

Hypnose: Les situations

Tous les soins anxiogènes pour le patient :

- aspiration
- Prise de sang
- Écouvillonnage de gorge
- Pose de Picc line
- Etc.....

Hypnose: Les Pré-requis

Information parents, patient, en parler à l'équipe avant.

Enquêter :

- ✓ Les passions
- ✓ Les intérêts
- ✓ Les rêves

Hypnose: Les modalités

- Avant tout vérifier que l'objectif est réalisable
- Le vocabulaire utiliser des formules positives
 - Ex : rassure toi à la place de ne t'inquiète pas
 - Laisser des blancs dans le discours en prévenant le patient
- La voix, le rythme
- L'enfant perçoit l'intention et le cadre
- Remercier l'enfant à la fin de la séance



Hypnose: Séance type

- Prise de contact
- Induction
- Travail de l'hypnose
- Retour à l'état ordinaire de conscience
- debriefing



Hypnose: L'induction

- Écoute des bruits
- Images métaphorique ex prise de sang = plombier
- Éloignement dans l'imaginaire
- Bulles de savon
- Le conte métaphorique : ne pas donner la solution, laisser les interrogations (ne nécessite pas d'induction)



Hypnose: Les 5 étapes de l'état hypnotique (Bioy 2015)

1 Modification de l'orientation temporo-spatiale

Légèreté /lourdeur, temps

2 Sentiment de détente mentale

sensation de relâchement

3 Hyper absorption de l'attention

attention facilement concentrée et focalisée

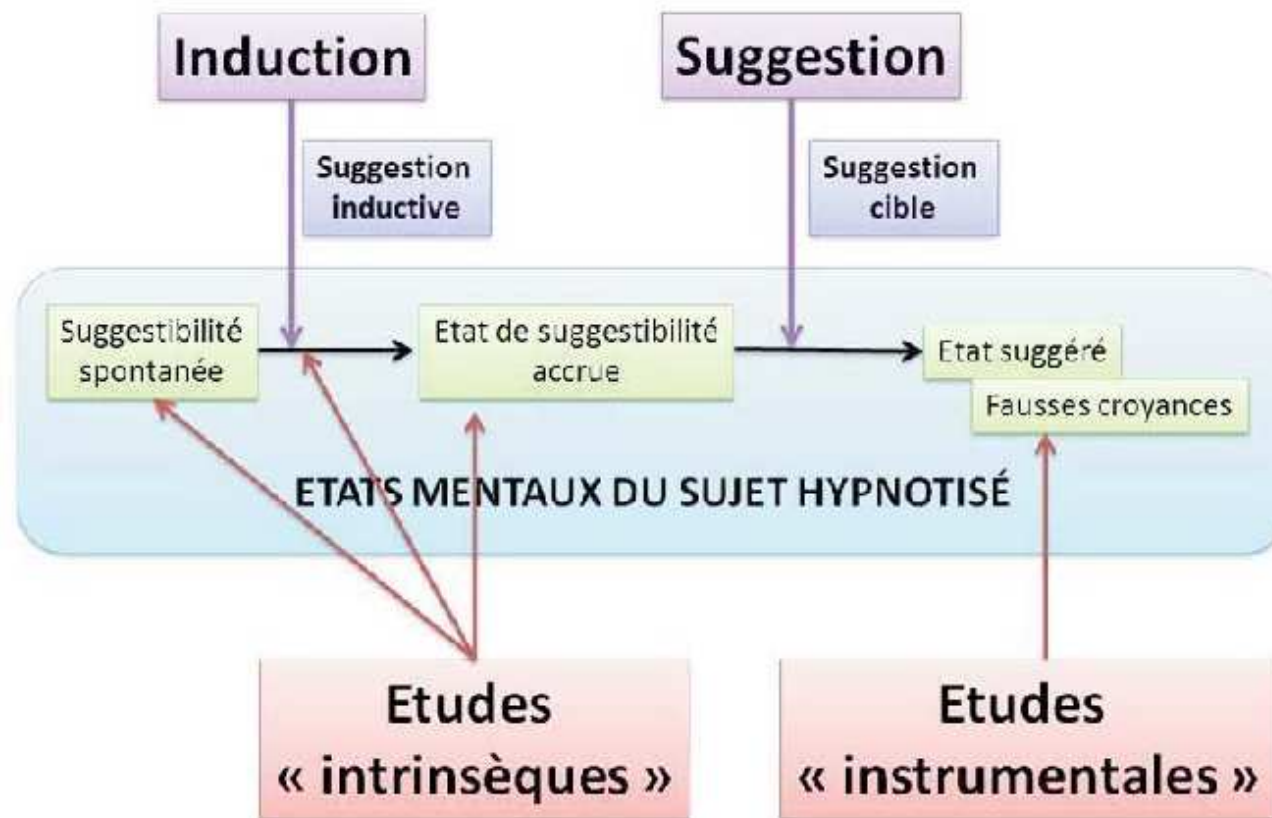
4 diminution du jugement et de la censure

le patient entre dans une logique proche des rêves

5 Expérience de réponse quasi automatique

le patient n'a pas l'impression d'agir (main)

- La suggestion consiste à faire dans l'esprit des autres une petite incision où l'on met une idée à vous. Victor Hugo



Hypnose et imagerie

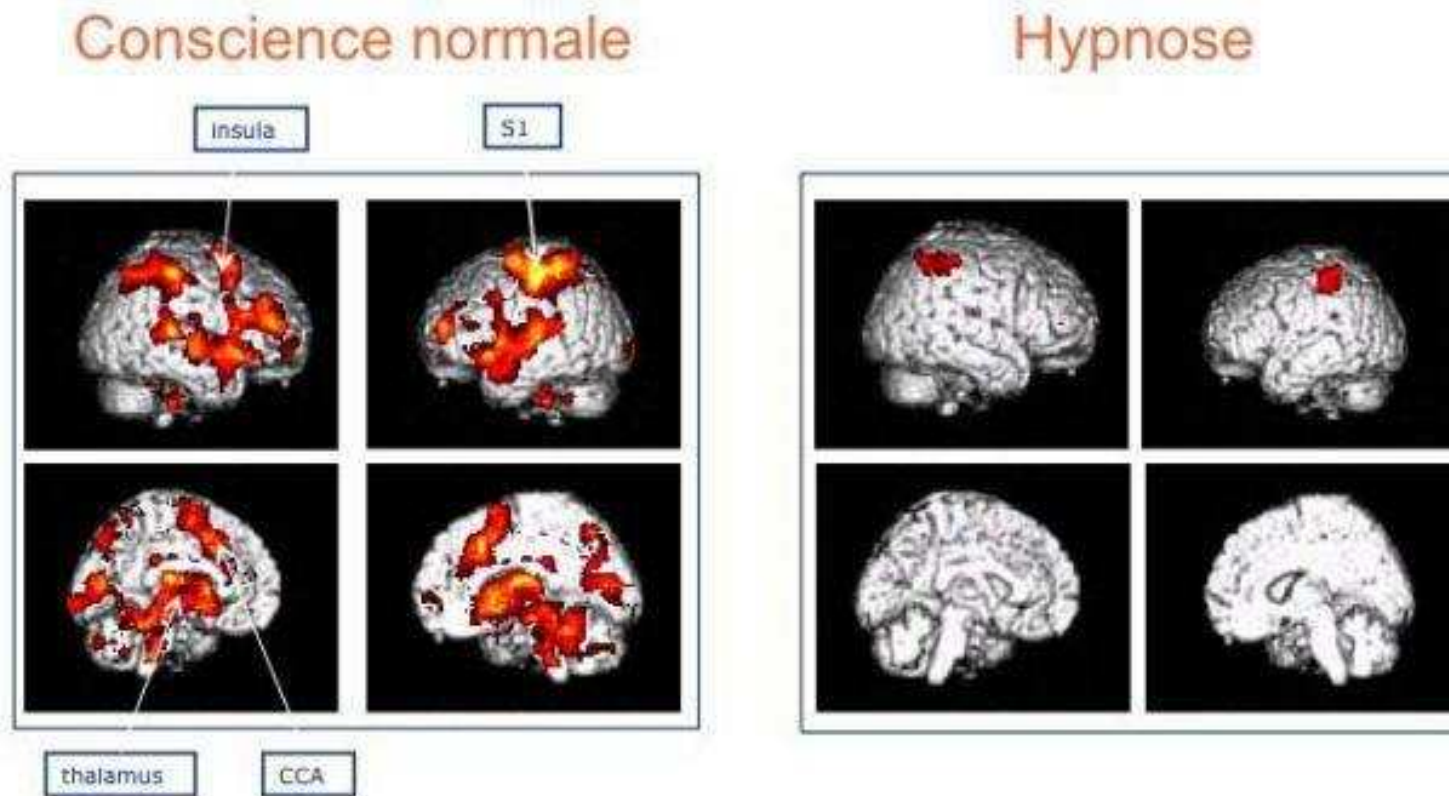


Figure 1. Représentation des zones cérébrales activées lors d'une stimulation douloureuse en état de conscience normale (panneau gauche) ou en hypnose (panneau droit). En état de conscience normale, le cortex cingulaire antérieur (CCA) et le réseau neuronal impliqué dans la douleur (cortex pré-frontal, aire motrice pré-supplémentaire (S1) striatum, cortex insulaires et périgénuais, thalami et tronc cérébral) sont activés. En état hypnotique, l'activation de ces régions par les stimuli douloureux est atténuée.

L'hypnose ce n'est pas

- **DORMIR**: tu peux même garder les yeux ouverts, bouger, parler pendant la séance...
- **DE LA MAGIE**: c'est un moyen de soigner et les personnes qui l'utilisent travaillent dans la médecine et ont une formation spécialisée en hypnose.
- **UN POUVOIR**: il existe un code « éthique » pour pratiquer l'hypnose médicale (c'est-à-dire des règles) ainsi le thérapeute ne peut pas te faire faire ce que tu ne veux pas faire...
- **UN SERUM DE VERITE**: ...ni te faire dire ce que tu ne veux pas dire.
- **UN REMEDE MIRACLE**: c'est un moyen supplémentaire de soulager la douleur, associé à d'autres moyens. Cela peut permettre de prendre moins de médicaments.

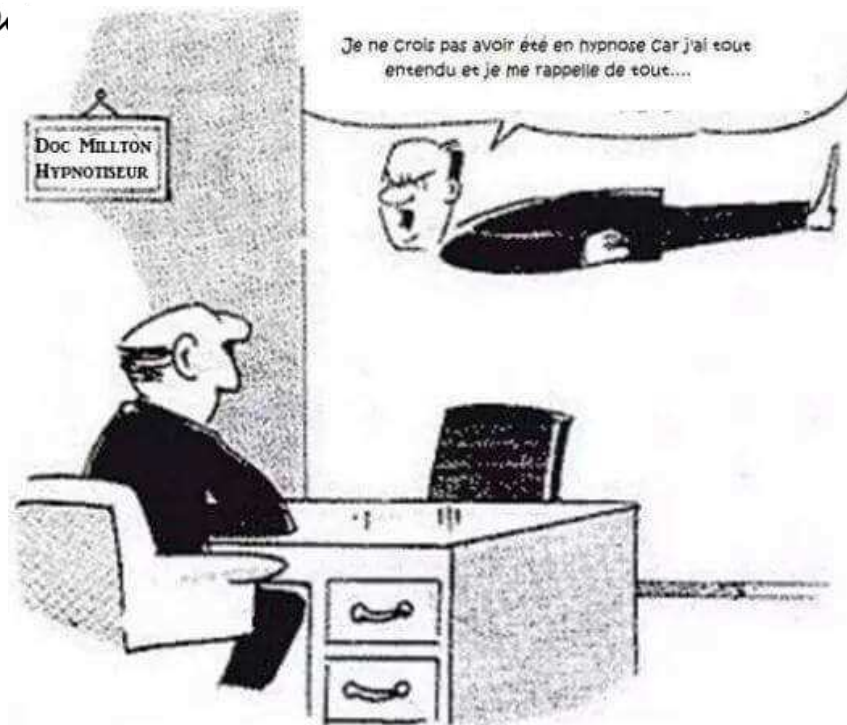


... et vous êtes heureuse de payer mes honoraires car dès que vous aurez signé ce chèque, une agréable sensation de relaxation se répandra dans tout votre corps...



**Clinique
d'hypnose
clinique**

Brumer



Quelles prises en charges alternatives?

- Contact humain, réassurance, information et implication du patient dans ses soins
- Médecine personnalisée, consultation douleur *Munck A et al. J of Cystic Fibrosis, 2012*
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- Hypnose
- Musicothérapie
-

La Musicothérapie: Principes

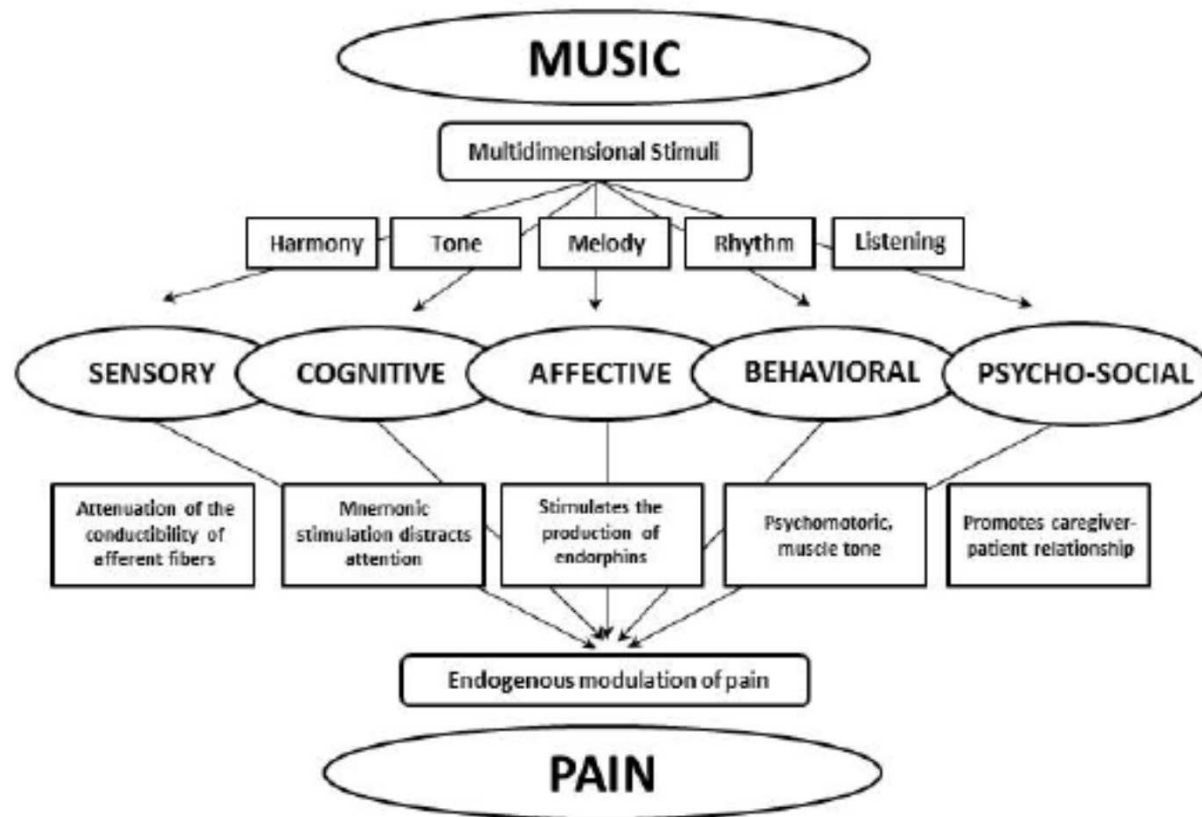


Figure 1. Main modes of psychophysiological measures of music therapy

La Musicothérapie: Principes

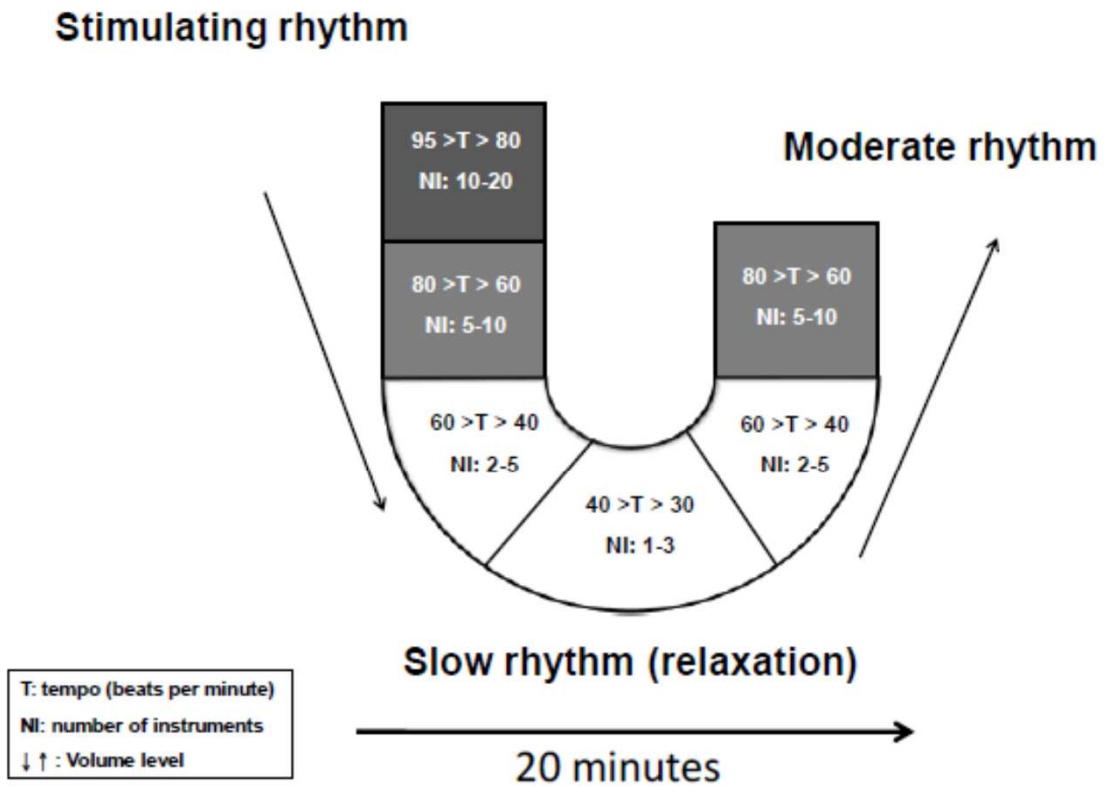


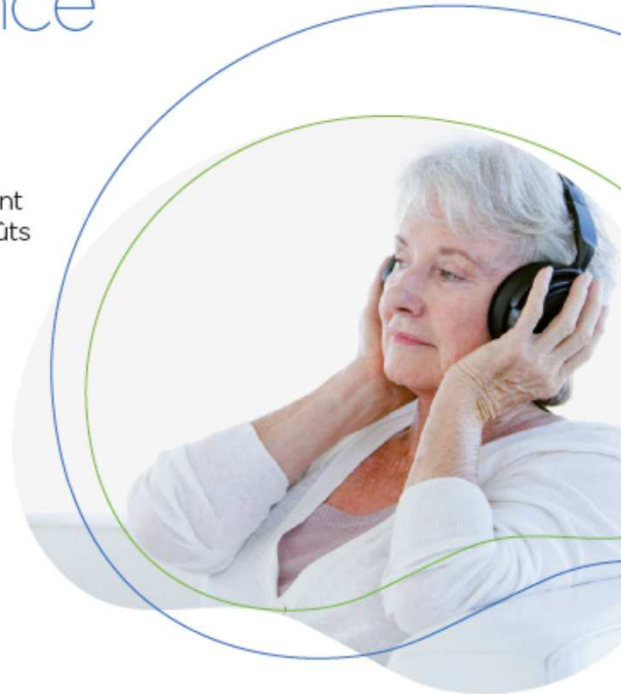
Figure 2. Technical standardized music therapy. The "U" sequence

La Musicothérapie: Principes

Une expérience sur-mesure

MUSIC CARE repose sur une **expérience personnalisée** : le patient choisit sa séance en fonction de ses goûts musicaux susceptibles de l'amener à la détente (jazz, musique classique, musique du monde, etc.).

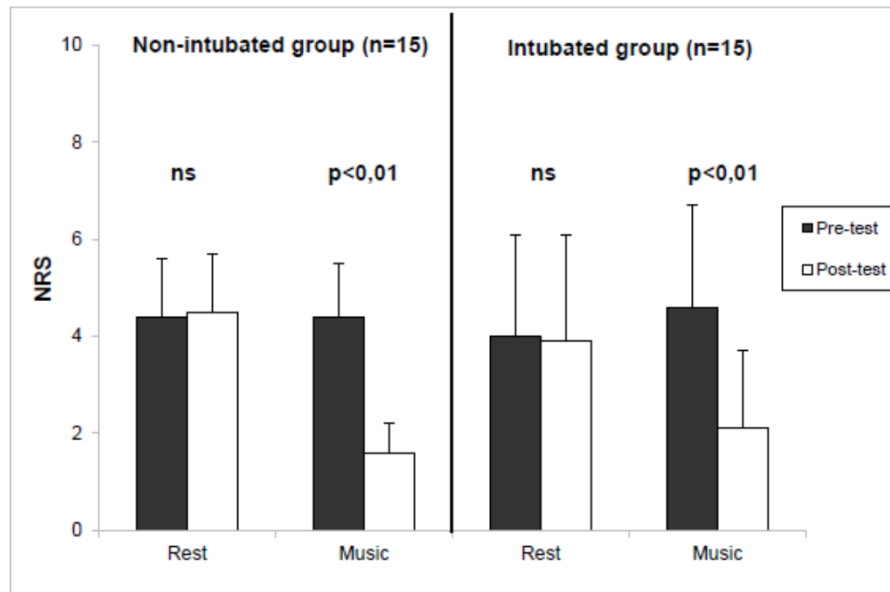
MUSIC CARE est accessible depuis n'importe quel ordinateur ou tablette. **L'équipe soignante** coordonne les séances en fonction des données personnelles, des besoins, de la pathologie de chaque patient et des objectifs thérapeutiques.



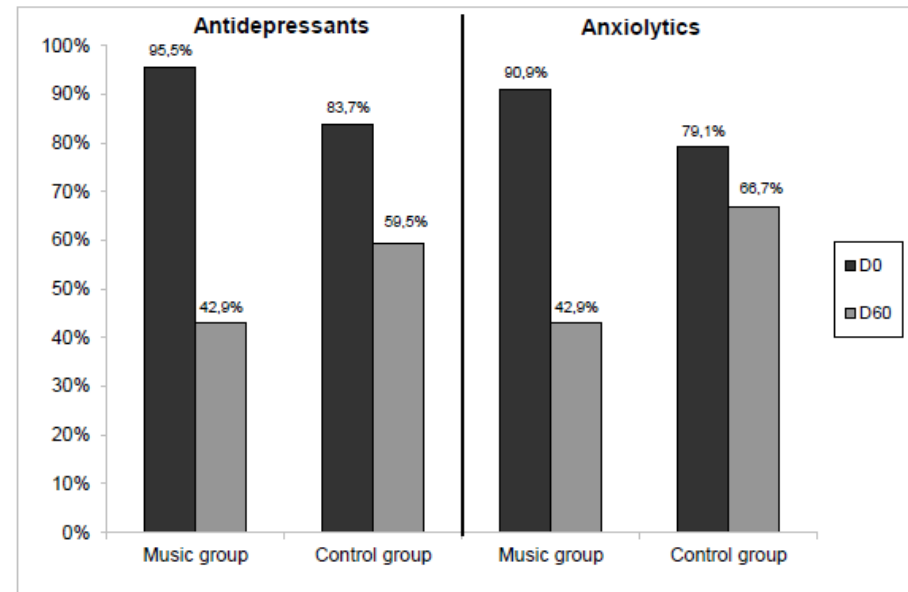
MUSIC CARE permet aux équipes soignantes, formées au préalable, de prescrire un **programme personnalisé** pour chaque patient. Ce dernier pourra ensuite poursuivre simplement son traitement à domicile sur www.music-care.com.

La Musicothérapie: Résultats

Douleur aiguë



Douleur chronique



Protocole en cours d'élaboration à l'hôpital Cochin portant sur la douleur ressentie lors de la réalisation de gestes invasifs chez les patients mucoviscidosiques sous musicothérapie versus contrôle

Quelles prises en charges alternatives?

- Contact humain, réassurance, information et implication du patient dans ses soins
- Médecine personnalisée, consultation douleur Munck A et al. J of Cystic Fibrosis, 2012
- Kinésithérapie et massages Lee A et al. J of Cystic Fibrosis, 2009
- Ostéopathie Hubert D et al. J of Cystic Fibrosis, 2014
- Hypnose
- Musicothérapie Jaber S et al. Annales françaises d'anesthésie et de réanimation anest, 2007; Guétin S et al. Ann Med Readapt Phys 2005
- Yoga, Sophrologie, Acupuncture...

Les prises en charges alternatives de la douleur: Conclusions

La douleur n'est pas qu'un symptôme mais une affection supplémentaire à traiter

Une meilleure évaluation de la douleur (quantitative et qualitative)

Une médecine personnalisée selon les besoins des patients

De nouvelles études d'évaluation des méthodes alternatives sont nécessaires



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Approche thérapeutique non médicamenteuse

- La rééducation
- Application chaud/froid
- Massages, balnéothérapie
- Neurostimulation
- Etirements, levées de tension
- Ostéopathie
- Relaxation, hypnose
- Sophrologie
- Relation d'aide

■ Les étirements et les levées de tension:

- Limitent les tensions musculaires, les contraintes articulaires et permettent de lutter contre une attitude vicieuse ou posturale de défense

■ L'ostéopathie:

- Est une méthode de soins qui s'emploie à déterminer et à traiter les restrictions de mobilité qui peuvent affecter l'ensemble des structures composant le corps humain (musculo squelettique, viscérale, crânienne ...)

■ La rééducation:

- un mode ventilatoire de confort, le respect de la CRF du patient, une progressivité rigoureusement dosée, renforcer positivement les bénéfices obtenus après chaque soin, la variété des exercices proposées participent à l'acceptation d'un soin jugé contraignant sur le long terme