La métasynthèse : une méthode de synthèse des données qualitatives appliquée aux soins psychiques de l'adolescent

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Titre

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Résumé

La méthode qualitative est en plein essor en médecine et particulièrement en psychiatrie, où la place du sujet, et ses représentations de la maladie et du soin sont centrales dans la prise en charge. Dans le champ de la santé de l'adolescent, de grands travaux permettent des avancées importantes dans la compréhension de la souffrance et les propositions de soins. Les méthodes qualitatives sont pourtant souvent critiquées de par leur contextualité et leur manque de pouvoir de généralisation. Une façon d'améliorer ces deux aspects consiste à appareiller les études traitant la même problématique de manière à en synthétiser les principaux résultats. Cet exercice de synthèse, notablement différent de celui de méta-analyse propre à la recherche quantitative, est réalisé depuis longtemps dans le champ des sciences humaines. Il s'agit de la métasynthèse. L'exercice de synthèse de la littérature est aujourd'hui de plus en plus codifié en recherche scientifique. Pourtant, certains points sont toujours en discussion – critères d'inclusion des études, critères de qualité des études. De plus, aucune équipe psychiatrique ne s'est appropriée l'outil de la métasynthèse pour l'adapter à la discipline.

Ce travail décrit les étapes de la construction et de l'adaptation, à partir du corpus existant, d'une méthode rigoureuse, effective, simple à transposer et enseigner, permettant la métasynthèse de données de la littérature dans le domaine du soin psychique de l'adolescent. Il s'agit d'une part d'une réflexion théorique, épistémologique et méthodologique sur les métasynthèses et leur adaptation au champ de la clinique psychiatrique. Et d'autre part d'une construction pratique, réalisée à partir de métasynthèses effectuées sur des thématiques du soin psychique de l'adolescent.

Les deux premiers articles sont deux travaux de métasynthèse. Le premier concerne l'obésité de l'adolescent. Les résultats obtenus mettent en lumière les limites de la méthode utilisée. Le deuxième article s'intéresse à la question des comportements suicidaires à l'adolescence. Les enseignements méthodologiques du premier article ont permis de perfectionner la méthode de métasynthèse. Enfin, le troisième article propose une description détaillée des étapes de la méthode construite.

En discussion, nous resituons la méthode de la métasynthèse dans le contexte historique du niveau de preuve scientifique. Nous montrons avec la littérature récente les liens toujours plus forts qui se construisent entre la méthode de la métasynthèse, aujourd'hui appelée *Qualitative Evidence Synthesis*, et la médecine fondée sur les preuves.

La métasynthèse est une méthode actuelle, qui montre tout son intérêt dans la recherche médicale. Cette méthode appliquée à la psychiatrie de l'adolescent est rigoureuse et fiable, et permet d'accroître la connaissance scientifique et d'améliorer la prise en charge des patients.

Mots Clés

Méthode qualitative, métasynthèse, psychiatrie, adolescent

Title

Metasynthesis: a qualitative evidence synthesis method implemented into adolescent mental care

Abstract

Qualitative research is expanding fast in medicine and especially in psychiatry, where the patient and his representations of illness and care are central to treatment. In the field of adolescent health, great work provides important advances in the understanding of suffering and care. Qualitative methods are however often criticized because of their contextuality and their lack of generalization power. One way to improve these aspects is to match studies addressing the same issue so as to synthesize the main results. From a long time, human sciences have taken hold of this exercise of synthesis, which is significantly different from meta-analysis of quantitative research. They have called this work metasynthesis. The literature synthesis exercise is now increasingly codified in scientific research. However, some points are still under discussion – For example, inclusion criteria for studies, study quality criteria –. Moreover, no metasynthesis exist in the field of psychiatric research.

This work describes the stages of construction and adaptation of a simple, rigorous, efficient, easy to share and teach method, which enables to do qualitative data synthesis in the field of psychological care to adolescents.

On the one hand, we propose a theoretical, epistemological and methodological reflection on metasyntheses and their adaptation to the field of psychiatric care. On the other hand, we describe a practical progression: our method is built from metasyntheses conducted on two themes of adolescent psychological care.

The first two papers are both metasyntheses. The first one is about adolescent obesity. The results highlight the limitations of the method we used. The second article focuses on the issue of suicidal behavior in adolescence. The methodological lessons of the first article helped us to improve the meta-synthesis method. The third article provides a detailed description of each steps of the method.

In discussion, we propose to situate the method of metasynthesis in the historical context of the scientific evidence. We illustrate with recent papers the increasingly strong links that exist between metasynthesis, now called Qualitative Evidence Synthesis, and Evidence-Based Medicine.

The metasynthesis is a modern method. It shows its interest in medical research. This method applied to adolescent psychiatry is rigorous and reliable, and can increase scientific knowledge and improve the care of patients.

Key Words

Qualitative method, metasynthesis, qualitative evidence synthesis, psychiatry, adolescent

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« *Si tu veux parler de l'universel, parle de ton village* »

Léon Tolstoï, *Guerre et Paix*

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Liste des abréviations

CQIM Group : Cochrane Qualitative Implementation and Method Group

EBM : Evidence-Based Medicine, Médecine fondée sur les preuves

RCT : Randomized-Control Trial, Essai Contrôlé Randomisé

INTRODUCTION

On ne saura jamais si nous vivons à l'extérieur ou à l'intérieur de la Terre… Cette idée peut sembler absurde, insensée, contraire à l'intuition et à l'expérience. C'est pourtant la thèse défendue par un mathématicien égyptien, Mostafa AbdelKader, et publiée en 1983 dans une revue de physique australienne (Abdelkader, 1983). Le chercheur applique une inversion par rapport à la sphère : à chaque point considéré comme extérieur à la Terre correspond un point intérieur. La question de la taille de l'univers est réglée par la géométrie : plus un objet est éloigné de la Terre, plus son image par inversion sera petite. Dans cet *univers concave*, nous habiterions à la surface interne de la Terre. Celle-ci serait creuse, et les étoiles les plus lointaines seraient les plus proches du centre qui resterait innaccessible. Les questions telles que la vitesse et la propagation de la lumière, la propagation du temps, la perception visuelle d'une terre ronde, sont expliquée et justifiées scientifiquement. Et la communauté scientifique s'accorde à dire que *l'univers concave* est une théorie non seulement plausible, mais irréfutable empiriquement.

Cette illustration est issue de la plus « dure » des sciences : les mathématiques. En mathématiques donc, la perspective est une notion discutée et sujet à débat. Car si personne ne croit au modèle de l'univers concave, celui-ci possède le même pouvoir prédictif et explicatif que le modèle aujourd'hui retenu. Le changement de point de vue qu'il impose n'invalide pas sa rigueur et sa valeur scientifique. Deux représentations mathématiques opposées de la réalité peuvent ainsi co-exister sans qu'une démarche empirique ne puisse invalider l'une ou l'autre. Cette illustration nous permet d'introduire l'idée que la connaissance est toujours une **représentation de la réalité** (St-Cyr Tribble & Saintonge, 1999, p. 115).

Mais alors comment avons nous fait le choix du modèle de l'univers convexe tel que nous le concevons aujourd'hui ? Les scientifiques confrontés à ce type de dilemne font souvent appel au principe dit du rasoir d'Ockham, encore appelé principe de simplicité ou d'économie : entre deux explications équivalentes, la plus simple est la meilleure. « Si nous avions toujours cru en ce modèle [de l'univers concave], nous aurions tout simplement inventé une autre physique » (Kouneiher, 2016) **La connaissance touche ainsi à l'opinion, à la croyance**. La

connaissance serait « toujours l'opinion ou la croyance de quelqu'un [et] n'existerait même pas à l'état pur » (St-Cyr Tribble & Saintonge, 1999, p. 115). La science constitue l'ensemble des connaissances fondées « *soit sur des principes évidents et des démonstrations, soit sur des raisonnements expérimentaux, ou encore sur l'analyse des sociétés et des faits humains.* » (Blay, 2006, p. 734). Bien qu'elle soit un savoir reconnu et approuvé socialement, la science demeure un ensemble de connaissances et donc d'opinions et de croyances subjectives (St-Cyr Tribble & Saintonge, 1999).

La subjectivité a toujours été au cœur des débats sur la recherche qualitative : celle du participant, celle du chercheur, celle des résultats discutés et interprétés à la lumière des subjectivités de chaque auteur contribuant à la littérature scientifique. C'est à partir de notre subjectivité de clinicien que nous nous sommes intéressés aux aspects épistémologiques et méthodologiques de la méta-synthèse. Notre expérience de l'engagement clinique auprès de jeunes patients adolescents a fait naître en nous le désir d'entretenir cet engagement dans la recherche. La recherche qualitative permet cela. La mise en perspective des points de vue des différents participants et leur interprétation en un tout original nous a séduit.

La primauté du mouvement de l'Evidence-Based Medicine (EBM) dans la constitution du savoir médical actuel nous préoccupe : quelle place la recherche qualitative peut-elle y trouver ? Sa spécificité, sa contextualité, sa dispersion, en sont ses principaux points de fragilité. Face à l'hégémonie des méta-analyses, point d'orgue du niveau de preuve scientifique, quel type de preuve propose la recherche qualitative ? Nous avons trouvé des éléments de réponse dans les discussions épistémologiques et méthodologiques qui animent les chercheurs sur les métasynthèses qualitatives.

Les métasynthèses intéressent de plus en plus les acteurs de santé publique qui les conçoivent comme des outils indispensables pour compléter, approfondir et préciser les protocoles de soins issus des méta-analyses quantitatives (Sandelowski, 2004). De multiples briques ont été ajoutées à l'édifice des méthodes de métasynthèses, et aujourd'hui, elles sont devenues une approche complémentaire et crédible aux méta-analyses quantitatives.

Ces arguments se sont imposés à nous dans l'élaboration de notre sujet d'étude. Nous avons choisi de nous intéresser aux métasynthèses, et en particulier à leur application à la recherche clinique psychiatrique. Ce travail retrace la construction d'une méthode de métasynthèse adaptée à nos sujets d'études.

Dans une première partie, nous présenterons le contexte de notre travail. Nous définirons les principaux éléments d'étude, et proposerons une mise en contexte de la recherche qualitative et de la métasynthèse.

Puis, après une description de la méthode utilisée pour la construction de notre méthode, nous présenterons les trois articles qui constituent les résultats de notre recherche.

Le premier article est une métasynthèse qualitative qui s'intéresse à l'obésité de l'enfant et de l'adolescent à travers les perspectives adolescentes, parentales et soignantes.

Le deuxième article est également une métasynthèse qualitative qui s'intéresse aux comportements suicidaires de l'adolescent et du jeune adulte, avec la même triple perspective.

Enfin, le troisième article présente la construction et l'élaboration de notre méthode. Il est l'aboutissement de notre travail puisqu'il résume la méthode construite et la discute au regard de la littérature.

Dans la discussion générale nous nous attacherons à inscrire la métasynthèse dans le mouvement de l'EBM. Nous clôturerons ainsi la boucle qualitative qui irrigue toute notre démarche scientifique : à partir d'une construction de la connaissance proposée par le participant, sa déconstruction dans l'analyse qualitative aboutit à une reconstruction subjective et scientifique originale ; à partir d'un débat autour de l'intérêt des méta-synthèses dans la construction de la connaissance, la mise en place de notre méthode conduira à un effort de réinscription dans l'élaboration des preuves scientifiques.

CONTEXTE

1. Définitions

1.1. La recherche qualitative

Il semble que la définition de la recherche qualitative soit aussi complexe que les objets qu'elle se propose d'étudier. On pourrait proposer comme définition générale *une forme d'investigation du sens à la fois systématique et empirique* (Shank, 2006), ou *un mot chapeau désignant les recherches qui décrivent et expliquent les expériences personnelles, les comportements, les interactions, et les contextes sociaux* (Razafsha et al., 2012). Ces quelques mots permettent d'entrevoir la complexité et la richesse des modalités de recherche possible au sein de cette entité ''qualitative''. Il est important lorsqu'on tente cet exercice de définition de ne pas vouloir trop préciser au risque d'introduire des éléments inscrits dans un corpus théorique qui excluraient tout ou partie de la recherche qualitative.

Pour débuter, trois éléments semblent communs à toutes les recherches qualitatives : l'importance donnée à la contextualisation des données – la recherche doit être menée en contexte et les données du contexte sont exploitées pour construire du sens – ; les données étudiées sont toutes des productions humaines, qu'elles soient issues d'entretiens, de récits, d'écrits, de données visuelles, d'observations… ; enfin, la recherche qualitative n'a pas pour objectif de prouver mais de proposer des hypothèses.

Partant de ce constat, nous proposerons deux étapes à cette tentative de définition : par une approche catégorielle, nous définirons la recherche qualitative en opposition à la recherche dite quantitative ; par une approche dimensionnelle, nous tenterons de mieux rendre compte de la complémentarité des approches en recherche médicale.

1.1.1. Approche catégorielle de la typologie de recherche

La recherche qualitative est souvent définie en opposition à la recherche quantitative. La recherche quantitative s'est en effet imposée comme gold-standard ces trente dernières années, à tel point que la définition de la recherche

médicale et celle de la recherche quantitative sont quasiment superposables ! L'hégémonie de *l'evidence-based medicine* (EBM) a introduit la notion de critères de preuve scientifiques dont l'utilisation excessive a occulté une grande partie de la recherche médicale existante. Cependant, les limites de l'EBM sont aujourd'hui de plus en plus évidentes : « *un résumé des résultats d'un essai contrôle randomisé dans un guideline de bonnes pratiques ne permet pas de renouveler les programmes et pratiques de soins* » (Goering, Boydell, & Pignatiello, 2008). Des études doivent permettre de repenser le soin en répondant non seulement à la question *Est-ce que cela marche ?*, mais également *Comment ça marche ?, Est-ce que ça va continuer à marcher ?, Est-ce que c'est acceptable ?* dans différentes situations. Là où les recherches quantitatives viennent fournir des vérités universelles en termes chiffrés, les recherches qualitatives proposent des données contextuelles sur la compréhension des mécanismes en jeu et l'implémentation des soins en contexte réel (Goering, Boydell, & Pignatiello, 2008).

On pourrait donc proposer une première définition en creux de la recherche qualitative : ce n'est pas ce qui est de la recherche quantitative (Fossey, Harvey, McDermott, & Davidson, 2002). Le qualitatif ne s'intéresse pas aux chiffres, ne propose pas de mesure, ne calcule pas de *p*, d'écart-type ou de lien de causalité. Glaser et Strauss, les concepteurs de la *Grounded Theory*, définissent la recherche qualitative comme « *tout type de recherche qui produit des données qui ne sont pas issues de procédures statistiques ou d'autres moyens de quantification* » (Glaser & Strauss, 1967). Les recherches qualitatives ne permettent pas de répondre à des questions du type combien ? dans quelle mesure ? Elle ne cherche pas la représentativité d'une population.

Au contraire, la recherche qualitative s'intéresse aux mots, aux discours, aux attitudes, aux comportements. Elle n'assume pas la simplification théorique d'un concept en une valeur numérique. Elle appréhende le phénomène dans toute sa complexité et sa contextualité. Elle cherche à répondre aux questions du type *comment, pourquoi*. Elle cherche à représenter les différents points de vue, les différentes perspectives sur une thématique donnée – par exemple, une étude qui s'intéresse aux soins proposés aux adolescents pourra interroger des

adolescents, des parents, et des soignants –(Aubin-Auger, Mercier, Baumann, & Lehr-Drylewicz, 2008; Goering et al., 2008; Razafsha et al., 2012).

Le paradigme de pensée des deux recherches est également le lieu de tensions : positiviste pour le quantitatif, la conception est celle d'une réalité unique, intrinsèque, observable par l'expérience reproductible ; constructiviste pour le qualitatif, la vérité née de l'interaction entre le sujet, l'objet, et le monde (Mays & Pope, 2000). Le paradigme constructiviste assume une position subjective de la réalité. L'importance est donnée au détail du contexte, qui, dans l'échange avec le chercheur, va prendre un sens particulier ; particulier qui permet, à partir d'une démarche interprétative, de conceptualiser des hypothèses universelles. La démarche quantitative est inverse : on part de la théorie, c'est-à-dire de l'universel, et on cherche à vérifier que cette théorie s'applique au particulier. Pour certains auteurs, la recherche qualitative, par son approche compréhensive, permet d'explorer « *le lien entre la "vraie vie" du clinicien et la science dure. Par exemple, seule la moitié des patients dépressifs vus en soins primaires sont concernés par les référentiels. Pourquoi ? La recherche qualitative a ici toute sa place pour explorer et expliquer ce type de décalage entre référentiels et pratiques médicales* » (Aubin-Auger et al., 2008).

Ainsi, si la psychiatrie est reliée aux processus psychiques et aux comportements, et que ceux-ci sont bien d'avantage subjectifs qu'objectifs, cette branche de la médecine aurait *gagné* son unique objectivité avec le développement de la recherche quantitative (Razafsha et al., 2012). On pourrait donc considérer que la recherche quantitative touche à une réalité objective tandis que la recherche qualitative, une réalité subjective. Pourtant, le paradigme positiviste impose de réduire la réalité à des données chiffrées quantifiables (INSERM, 2004, p. 4). On crée ainsi une réalité abstraite qui est moins complexe que la réalité mais qui est accessible à la mesure. Par cette idée, on peut considérer que la réalité mesurée par le quantitatif est également une réalité subjective, le fruit de la conception des chercheurs qui ont conçu le protocole de recherche.

Les méthodes qualitatives cherchent à décrire une structure complexe, en dégager une théorie, produire des hypothèses. Dans cette idée, elle adopte le plus

souvent une démarche inductive, c'est-à-dire qu'elle ne nécessite pas d'hypothèse formulée au préalable. Les hypothèses émergent du matériel, du contexte de la co-construction de la réalité par le sujet et le chercheur : c'est le concept de la *Grounded Theory* (Glaser & Strauss, 1967). Le chercheur est ainsi encouragé à mettre de côté ses conceptions théoriques et à limiter l'étude bibliographique au minimum avant l'étude, afin d'être attentif aux hypothèses émergentes. L'analyse des données doit être effectuée en parallèle au recueil, avec des allers-retours circulaires entre le matériel et l'interprétation, pour faire naître du sens à partir du matériel (Mays & Pope, 1995).

Enfin, les critères de validité des études quantitatives, définies selon les principes positivistes (reproductibilité, validité interne, validité externe, …) sont difficilement applicables à la recherche qualitative. Pourtant, la recherche qualitative doit se soumettre à des critères de rigueur pour prétendre être de la recherche scientifique. La subjectivité assumée en recherche qualitative est à l'origine des principaux critères de rigueur scientifique. L'importance de la généralisation possible ne dépend pas de critères classiques statistiques, mais plutôt de la qualité de la description méthodologique, de la rigueur et de la prudence des interprétations, ainsi que de la puissance des résultats obtenus. C'est aussi ce qui fait la force de ce type d'étude : la réalité n'existe que dans cette co-construction. L'objectif de neutralité du paradigme quantitatif ne serait qu'un leurre : « *la perspective de l'observateur est toujours limitée et détermine ce qui peut être vu. Cette notion s'applique même dans la science de laboratoire.* » (Malterud, 2001) La méthode qualitative possède donc des critères de crédibilité et de pertinence spécifiques et rigoureux.

Il existe de nombreuses publications d'outils et de systèmes d'évaluation de la qualité des études qualitatives, plus d'une centaine selon Pocock et Al. (Pocock, Trivedi, Wills, Bunn, & Magnusson, 2010). Pourtant, la plupart de ces outils ne sont qu'une application pratique de critères théoriques communs, que certains auteurs ont bien théorisé (Brown & Lloyd, 2001; Malterud, 2001; Mays & Pope, 1995, 2000). Ces critères, assurant la validité ou crédibilité sont la triangulation, la validation par le sujet, la description fine des méthodes utilisées et la fiabilité inter-utilisateurs, la réflexivité, l'attention aux cas négatifs et l'équité.

La triangulation est l'utilisation de plusieurs sources de collection des données. Comparer les données issues de différentes sources permet de faire émerger des modèles de convergence corroborant une interprétation globale. S'il existe une faiblesse dans un type de recueil, les autres peuvent la compenser. La triangulation permet ainsi d'enrichir les données obtenues.

La validation par le sujet est le fait de permettre au sujet de lire et commenter le travail d'interprétation. Ces commentaires sont ensuite intégrés à l'analyse. Le fait que le sujet se reconnaisse dans la description du phénomène est un bon critère de crédibilité.

Le paradigme de départ suppose que la méthode utilisée influe sur le résultat obtenu. La description de la méthode de manière systématique et détaillée devrait permettre en théorie qu'un utilisateur entrainé puisse analyser les mêmes données de la même façon et obtenir des résultats semblables pour l'essentiel (Mays & Pope, 1995). L'analyse doit être également faite par plusieurs chercheurs, avec des bagages théoriques différents, afin de renforcer les résultats obtenus en commun.

Dans le même but, le background du chercheur doit être clairement défini, ainsi que le champ théorique dans lequel il se place pour effectuer l'analyse. C'est ce qu'on appelle la réflexivité. Il existe de multiples perspectives du monde, et le fait de clarifier sa position permet de diminuer les biais d'interprétation par le lecteur.

Les éléments qui viennent contredire l'explication émergente ne doivent pas être écartés, mais bien inclus dans l'explication. L'analyse consiste en un perpétuel va et vient entre le matériel et les interprétations émergentes. Elle doit être effectuée au fur et à mesure de la collection des données, afin de permettre de réorienter la recherche pour explorer entièrement la thématique. L'analyse doit tenir compte de tous les aspects observés afin de décrire l'ensemble du phénomène.

L'équité est le fait d'incorporer suffisamment de perspectives pour explorer complètement le phénomène. On peut, comme en quantitatif, utiliser des techniques d'échantillonnage statistiques, mais il est souvent difficile et non

essentiel d'utiliser ces techniques pour sélectionner les sujets de l'étude. Il est en revanche utile d'explorer les différents points de vue et de sélectionner les sujets exemplaires de l'étude, qui sont les sujets les plus informatifs, pour obtenir du matériel le plus riche possible. Le nombre de sujet à inclure est difficile à déterminer à l'avance, et c'est le fait de ne plus trouver de matériel nouveau dans l'analyse qui permet de conclure à la saturation de l'échantillon.

La pertinence d'une étude qualitative est évaluée par la nouveauté de l'information qu'elle apporte aux connaissances existantes d'une part, et par l'ampleur avec laquelle les données peuvent être généralisées. Mays & Pope précisent que la meilleure façon d'obtenir des données généralisables est de détailler au maximum le rapport de la recherche, afin que le lecteur soit capable de juger s'il observe les mêmes résultats dans des conditions identiques (Pope, 2000).

Ainsi, dans une perspective catégorielle, on peut schématiquement dessiner deux modèles de recherche dont les caractéristiques sont résumées dans le Tableau 1.

Approches qualitatives	**Approches quantitatives**
Réalité multiple, issue d'une construction, holistique	Réalité unique, tangible et décomposable
Termine par des hypothèses	Commence par des hypothèses
Description et construction	Expérience et contrôle
Le chercheur est un instrument de l'étude	Les instruments de l'étude sont formels
Milieu naturel	Expérience
Inductive	Hypothético-déductive
Interprétative	Prédictive
Construction de modèles théoriques	Analyse de variables
Vise la pluralité, la complexité	Vise le consensus, la norme
Fait peu usage des données numériques	Réduit la réalité à des données numériques
Inscription dans le contexte	Généralisation

Tableau 1 - Approches quantitatives et qualitatives (tableau adapté de (Razafsha et al., 2012))

1.1.2. Vers une approche dimensionnelle

L'approche catégorielle semble pourtant trop caricaturale et ne permet pas de rendre toute la complexité des interactions des différents types de recherche. Les experts s'autorisent de plus en plus aujourd'hui à dépasser les oppositions conceptuelles pour proposer une vision d'avantage dimensionnelle de la recherche : un pôle s'intéressant à quantifier, l'autre à qualifier, et, dans l'intervalle, de multiples positions intermédiaires et interrelations.

En ce sens, Mays et Pope défendent la position épistémologique d'Hammersley (1992), Becker (1993) et Kirk (1984) : le *réalisme discret* (Hammersley, 1992; Kirk & Miller, 1986; Mays & Pope, 2000). Toute recherche implique une perception subjective. Les différents types de recherche proposent différentes perspectives. L'objectif de la recherche scientifique ne serait pas *d'atteindre la vérité*, mais de *représenter la réalité*. Ce positionnement s'illustre parfaitement dans une science dite 'dure', la physique. La physique est la science des phénomènes naturels de l'univers. De par son objet d'étude, la physique apparait comme une science objective, inscrite dans un paradigme positiviste, et un but de chercher une vérité absolue. Pourtant, si on prend l'exemple de l'étude du mouvement et la constitution de la matière, les théories explicatives sont des constructions subjectives qui évoluent dans le temps. Jusqu'au XIXème siècle la théorie gravitationnelle était hégémonique, totipotente. Mais cette théorie a montré ses limites et Einstein puis ses successeurs ont proposé de multiples conceptions théoriques, et on sait aujourd'hui que ce qui est vrai à grande échelle (force gravitationnelle) ne l'est plus du tout à très faible échelle (force forte et force faible). Certains physiciens font même l'hypothèse que, dans les premiers instants du Big Bang, aucune des théories existantes ne pourraient s'appliquer. La physique, science dure, serait donc elle-même une description subjective et évolutive de la réalité.

Hammersley (1992) a déconstruit de manière systématique l'opposition quantitatif-qualitatif. Pour lui, « *la pratique effective de la recherche oblige à procéder, pour une connaissance adéquate des objets, à des combinaisons multiples de ces termes ou positions* » (Groulx, 1997, p. 5). De nombreux auteurs ont adopté le point de vue d'Hammersley, de manière plus ou moins rigoriste, certains allant

jusqu'à systématiquement utiliser quantitatif et qualitatif au sein d'une même étude (voir par exemple (Becker, 1961)).

Ainsi, si la place du chercheur – observateur extérieur, objectif et neutre en quantitatif, participant actif, subjectif influençant la construction des résultats en qualitatif – semble être une différence irréductible entre qualitatif et quantitatif, cette différence ne serait qu'une différence de perspective et non de paradigme.

Falissard et coll. (2013) pose la question de la place des nombres et des mots en recherche psychiatrique (Falissard, Révah, Yang, & Fagot-Largeault, 2013). Les auteurs proposent une taxonomie catégorielle qui permet de repenser les différences conceptuelles et épistémologiques des approches qualitatives et quantitatives. Leur taxonomie repose sur la double détermination de la manière de représenter les objets dans les données (littérales, globalement ou partiellement mathématiques), et la manière d'analyser et de relier ces données entre elles (herméneutique, statistique ou sous la forme d'équations). On peut ainsi imaginer six catégories de recherches dont des exemples sont données dans le Tableau 2.

		Les liens entre les données sont obtenues par		
		L'herméneutique	Les statistiques	Les équations
Représentation des objets	Litérales	La psychanalyse	L'anayse informatisée de texte	De nombreux mécanismes neurobiologiques
	Partiellement mathématiques	Les schémas A-B-A-B des études sur les thérapies cognitivo-comportementales	L'épidémiologie, la neuroscience cognitive, l'imagerie cérébrale	La pharmacocinétiques des psychotropes
	Globalement mathématiques	Le modèle des neurones miroirs	Pas en psychiatrie actuellement [thermodynamique]	Pas en psychiatrie actuellement [physique]

Tableau 2 – Proposition de taxonomie de la recherche psychiatrique adaptée de (Falissard et al., 2013)

Les réflexions multiples permettent d'approcher la complexité des liens entre quantitatif et qualitatif. Les tensions entre les multiples positions permettent d'animer cette réflexion. Cette complexité se retrouve à l'identique dans la définition des métasynthèses.

1.2. La métasynthèse

Métasynthèse est un mot-valise qui représente un regroupement de méthodes – groupe hétérogène de méthodes aux préjugés théoriques multiples – permettant la collecte systématique et la synthèse interprétative d'études qualitatives (Hannes, Booth, Harris, & Noyes, 2013; Kinn, Holgersen, Ekeland, & Davidson, 2013; Mohammed, Moles, & Chen, 2016; Ring, 2011). Les termes *revues qualitatives, synthèses qualitatives, revues d'études qualitatives, métasynthèses qualitatives, synthèses d'études qualitatives, synthèses thématiques, méta-ethnographies*, sont interchangeables : même si certains peuvent également désigner une méthode spécifique, tous sont employés comme synonyme de *métasynthèse.* Le Cochrane Qualitative Implementation Methods Group (CQIM group) a récemment choisi d'utiliser le terme *Qualitative Evidence Synthesis* (synthèse de preuves qualitatives) (Booth et al., 2016). Par habitude et pour plus de simplicitié, nous utiliserons dans notre travail indifféremment *métasynthèses* et *Synthèses qualitatives*.

Bien que très différentes dans leur déroulement, les *métasynthèses* proposent toutes une revue de littérature qualitative analysée à l'aide de méthodes interprétatives inspirées des études qualitatives. La revue et l'analyse s'effectuent souvent de manière simultanée, l'une influençant le cours de l'autre et inversement. Toutefois, on peut décomposer les deux principales étapes afin de les décrire.

La première étape est de proposer une revue de littérature qualitative sur une thématique donnée. En cela, la métasynthèse adopte une démarche qui s'apparente à d'autres méthodes de revue de littérature : scoping review –qui interrogent un vaste panel d'articles de méthodes différentes sur un thème étendu sans sélection systématique–, narrative review –revue narrative descriptive des résultats d'articles quantitatifs et qualitatifs sur une thématique donnée– ou encore méta-analyse –revue systématique ciblées sur une question précise avec combinaison des résultats statistiques quantitatifs. La sélection des études incluses pourra s'effectuer de manière systématique ou de manière raisonnée (purposive). Les critères d'inclusions pourront être définis a priori

comme dans les revues quantitatives, ou bien au cours de l'inclusion comme dans la méthode qualitative.

La deuxième étape est l'analyse des données. L'objectif n'est plus ici de proposer un résumé des résultats obtenus dans les différentes études incluses, mais bien d'effectuer une analyse interprétative des articles inclus. On souhaite atteindre un niveau interprétatif supérieur, une généralisabilité théorique plus grande (Barnett-Page & Thomas, 2009; Finfgeld-Connett, 2013; Lee, Hart, Watson, & Rapley, 2014; Noblit & Hare, 1988; Ring, 2011). Noblit et Hare (1988), fondateurs de la meta-ethnography, précisent que les chercheurs doivent aller au-delà des résultats de chaque étude pour transformer le tout en quelque-chose de plus grand que la somme de chaque partie : « *to make the whole into something more than the parts alone imply* » (Noblit & Hare, 1988). Chaque concept clé présent dans une étude sera systématiquement répertorié et relié aux autres puis à la littérature dans une perspective interprétative globale (Atkins et al., 2008; Barnett-Page & Thomas, 2009; Britten et al., 2002).

Le travail de métasynthèse peut ainsi être mis en perspective avec celui de méta-analyse qualitative : la méta-analyse propose une sélection rigoureuse d'articles scientifiques puis une analyse statistique globale des résultats de ces études. L'analyse statistique est souvent complexe, pondérée et le résultat (calcul de *l'effect size*) permet une interprétation d'un plus haut niveau de preuve et de généralisabilité. La métasynthèse peut être réduite schématiquement à une analyse qualitative d'analyses qualitatives (Zimmer, 2006). La nuance réside toujours dans la perspective, les objectifs que la recherche tente de remplir. En cela, la métasynthèse qualitative est « *fondamentalement plus herméneutique et plus ambitieuse sur le plan théorique, en ce sens qu'elle tente de comprendre et d'expliquer l'entièreté du phénomène observé* » (Kinn et al., 2013).

Le travail d'analyse interprétative permet d'atteindre un troisième niveau interprétatif. Le premier niveau est l'interprétation de l'expérience vécue par le participant. Le deuxième est l'interprétation du discours du participant par le chercheur des études incluses. Le travail de métasynthèse propose une interprétation intégrative des deux niveaux précédents (Atkins et al., 2008; Kinn et al., 2013; Lee et al., 2014; J. Thomas & Harden, 2008; Zimmer, 2006).

1.3. L'adolescence

Définir l'adolescence pourrait faire l'objet d'une thèse de doctorat… Comme le rappelle Brusset (2004), le plus simple est de définir la période de l'adolescence « *par ce qu'elle n'est pas : ce n'est plus l'enfance, ce n'est pas encore la maturité*. » (Brusset, 2004, p. 2181) Il est difficile de mettre des bornes à la période de l'adolescence, même si on est capable de constater qu'elle s'étend de plus en plus – à la fois vers le jeune âge, avec l'adultomorphisme de certaines jeunes filles par exemple, mais également au début de l'âge adulte, le *jeune adulte* partageant de nombreuses problématiques et psychopathologies communes avec l'adolescent à tel point que certains nomment cette période l'adulescence (Anatrella, 2003). Un certain nombre de phénomènes psychiques s'y passent, en lien avec les transformations physiques de la puberté et l'acquisition progressive d'un statut social d'individu adulte.

Mais résumer l'adolescence à la question de la puberté est une erreur. En effet, l'adolescence est un problème relativement récent dans la culture occidentale (Jaffré, 2008). L'adolescence en tant qu'entité individualisée n'existe pas dans toutes les cultures même si le passage de l'enfance à l'âge adulte est universel (Moro, 2015). « *La puberté est une condition nécessaire mais non suffisante de l'adolescence.* » (Brusset, 2004, p. 2181). Sur le plan neurocognitif, le développement et l'élargissement des capacités de l'intelligence, de la socialisation, de l'affectivité et de la sexualité comportent « *des remaniements de l'ensemble du fonctionnement mental et de l'organisation de la personnalité* » (Brusset, 2004, p. 2182). Sur le plan psychique, les modifications physiologiques imposent à l'adolescent de se reconfronter aux conflits délaissés durant la période de latence et se situer sur le plan de son identité sexuelle. Il devra faire le deuil d'une mégalomanie infantile et d'une bisexualité triomphante, quitter la toute puissance de l'état d'enfance pour un voyage intérieur « *vers cet étrange statut inconnu qu'est celui de l'être-adulte* » (Moro, 2010, p. 42).

L'adolescent est un être en questionnement : la première question, « qui suis-je ? » va induire la plupart des suivantes. Face aux modifications physio-psychologiques profondes, la menace sur le sentiment de continuité de l'existence est grande. L'adolescent se met à « penser ses pensées », et se pose

alors la question de l'origine de ces pensées : est-ce la sienne, celle d'un autre, celle d'un autre soi ? (Marcelli, 2014, p. 27). La construction des identifications va passer par les questions de « D'où je viens ? » (Filiation) et « A qui je peux faire confiance ? » (Affiliations). Enfin, il se demandera « Vers où je souhaite aller ? Qui je souhaite devenir ? ».

Enfin l'adolescent est un être social. La génération adolescente peut s'envisager en opposition aux cultures adultes, en rapport alors avec la question des conflits de générations. Mais en y regardant de plus près, ces contre-cultures sont de véritables cultures, les cultures adolescentes comme les nomme David Le Breton (Le Breton, 2008) ; cultures nées de l'indispensable et intarissable créativité adolescente (Moro, 2015, p. 16).

Dans ce travail, nous considèrerons une définition assez large de l'adolescence, telle que nous l'envisageons dans notre clinique quotidienne. Les limites d'âge étant floues, et variable en fonction des latitudes, nous nous concentrerons d'avantage sur une population d'individus qui présentent des tentatives d'adaptation aux difficultés externes ou internes similaires. Par exemple, en ce qui concerne la question du suicide et des comportements suicidaires, les experts considèrent que les adolescents comme les jeunes adultes partagent la même psychopathologie. Les grandes études incluent généralement des participants sur une fourchette d'âge assez large : 15-25 ans pour l'Organisation Mondiale de la Santé (WHO, 2014), voire 15-29 ans dans certaines études (Lachal, Orri, Sibeoni, Moro, & Revah-Levy, 2015).

1.4. Les soins psychiques

Le soin a pour origine étymologique le latin *somniare*, qui a donné à la fois soigner et songer. Apporter du soin à l'autre, c'est songer à lui, se soucier de lui, lui porter attention. Notre conception du soin est proche de celle développée par Jacques Hochmann : « *Soigner c'est protéger le malade autant contre les dangers extérieurs que contre la montée d'une violence sanguinaire, c'est calmer une douleur morale en procurant un baume, qu'il soit médicamenteux ou psychologique, et en apportant au souffrant assistance et réconfort. C'est écarter ce qui empêche une personnalité de se réaliser, ce qui arrache le soi au soi et l'aliène*. »

(Hochmann, 2014, p. 5). Le soin est un double travail, celui du patient qui a la lourde tâche de changer, de mobiliser des ressources et par là même se mettre dans une position instable afin d'arriver vers un mieux ; celui du soignant qui doit fournir un travail considérable reposant sur les « *souffrances par identificatio*n » (Gutton, 2004). Nous avons choisi le concept de soins psychique car à notre sens il recouvre une dimension plus large que le soin psychiatrique. Bien que les deux termes soient proches, psychiatrique sous-tend la notion de trouble ou de maladie constituée. Or notre position est celle d'un psychiatre d'adolescents pour lesquels tout est mouvement, construction, déconstructions et reconstructions. La souffrance psychique est tantôt exprimée par un syndrome constitué, mais peut dès la consultation suivante s'amender ou se transformer considérablement. Si l'adolescence est le lieu d'apparition de la plupart des grands troubles psychiatriques (psychoses, troubles de l'humeur, troubles névrotiques), ceux-ci sont le plus souvent atypiques et mouvants. Enfin, de nombreux troubles psychiques de l'adolescence s'expriment par des symptômes physiques (Brusset, 2004). Les douleurs, les modifications du comportement, sont exemplaires de ce rapport au corps à l'adolescence, corps qui est souvent l'écran de projection de la souffrance psychique. Nos travaux s'intéresseront donc à tous les aspects du soin psychique, parfois à l'interface du soin physique.

2. Contexte méthodologique

2.1. Le contexte de la recherche qualitative

2.1.1. Brève histoire de la recherche qualitative

Certains auteurs considèrent que la recherche qualitative remonte aux origines de l'humanité : les premiers hommes, lorsqu'ils ont commencé à explorer leur environnement, on observé, écouté, questionné, et interprété leur environnement à la manière d'un chercheur phénoménologue explorant son terrain (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998). L'avènement de

l'écriture a permis de pérenniser les données acquises, et de construire une base de connaissance qui n'a cessé de croître depuis.

Pourtant, c'est au début du XXe siècle que les questions de méthodologie émergent, et que les premières études définies comme qualitatives sont publiées. En sciences sociales, notamment en sociologie et en anthropologie, disciplines en cours d'individuation dans les années 1900, le développement de méthodes permettant d'étudier des phénomènes humains dans leur contexte naturel devient très vite indispensable. Parmi les grandes études qualitatives du début du XXe, ont peut citer les travaux de l'Ecole de Chicago, berceau de la sociologie, des méthodes qualitative et notamment de l'observation participante (méthode dite ethnographique) (W. I. Thomas & Thomas, 1928; W. I. Thomas & Znaniecki, 1918). Les méthodes qualitatives vont infiltrer toute la recherche en sociologie et anthropologie, de Margaret Mead jusqu'à aujourd'hui (Hammersley, 1990; Mead, 1928). Dès les années 1950, le marketing s'empare également des méthodes qualitatives, notamment des techniques d'entretien de groupes, les *focus groups* (Aubin-Auger et al., 2008).

Bien qu'on puisse considérer que certains types de recherches utilisant le cas unique s'apparente à la recherche qualitative – citons par exemple les travaux de Freud et des psychanalystes, qui étudient les participants dans le cadre de soin particulier de la cure analytique (Kvale, 1999)–, ce n'est que vers les années 1990 que les premières études qualitatives médicales sont publiées. Parmi les premières grandes études qualitatives en médecine, on peut citer l'étude de Morgan et Watkins (1988) sur la non-observance des traitements antihypertenseurs (Morgan & Watkins, 1988). Les méthodes qualitatives n'ont cessé depuis de progresser (Bradley, Curry, & Devers, 2007; Poses & Isen, 1998; Shortell, 1999), et le terme MESH (MEdical Subject Headings, thesaurus de la base de données Medline) *qualitative research* est apparu en 2003 (Aubin-Auger et al., 2008). Des recherches qualitatives sont proposées dans toutes les disciplines médicales, de la pédiatrie jusqu'à la chirurgie (Gill, Stewart, Treasure, & Chadwick, 2008; Morgan, Gibbs, Maxwell, & Britten, 2002; Orri, Revah-Lévy, & Farges, 2015). L'essor des méthodes qualitatives a lieu dans de nombreuses thématiques autour du vécu des patients comme des soignants et dans des

contextes multiples, dans les modalités de prise en charge, dans les questions d'efficacité thérapeutique… Mais cela prend du temps ! Une étude de 2003 s'est intéressée aux publications qualitatives de 6 grandes revues de médecine générale et psychiatrie (le British Medical Journal, le Lancet, le British Journal of General Practice, Family Practice, le British Journal of Psychiatry et Psychological Medicine). Entre 1995 et 2005, la proportion d'articles qualitatif dans ces revues augmente de 2,1%, passant de 4 articles sur 1163 en 1995 à… 32 sur 1359 en 2005 (Crawford, Ghosh, & Keen, 2003) !

De grandes études qualitatives ont proposées des avancées théoriques majeures dans le champ psychiatrique (Edwards & Gross, 1976; Russell, 1979). Régulièrement, d'importants travaux qualitatifs permettent des avancées importantes dans la compréhension des troubles psychiques, du vécu par les patients de la maladie, de la stigmatisation, ou des soins (Bilderbeck, Saunders, Price, & Goodwin, 2014; Crawford et al., 2008; Dinos, Stevens, Serfaty, Weich, & King, 2004; Perkins, Winn, Murray, Murphy, & Schmidt, 2004; J. Price, Cole, & Goodwin, 2009; Serpell, Treasure, Teasdale, & Sullivan, 1999; Sinclair, 2005; Sinclair et al., 2012).

2.1.2. La proximité des perspectives qualitatives et cliniques psychiatriques

Dans un éditorial d'*Acta Psychiatrica Scandinavica* de 2008, Sranghellini et Ballerini s'interrogent sur le risque tautologique de la tendance de la recherche récente à n'utiliser que des entretiens structurés visant à mesure la subjectivité des patients psychiatrique. Ce type d'études pourrait étouffer les récits et significations issues des participants au profit de schémas cliniques préétablis (Stanghellini & Ballerini, 2008). Il est vrai que la recherche qualitative possède cet intérêt qu'elle autorise le chercheur *naïf* à se laisser immerger par le contexte, se laisser surprendre par l'expérience du patient *expert* (Whitley & Crawford, 2005). Bien d'avantage que la recherche psychiatrique classique, la recherche qualitative permet de générer des données originales et des hypothèses inédites. A notre sens, la méthode qualitative est très proche de la démarche clinique psychiatrique : de par l'importance donnée au contexte, le

positionnement du sujet comme celui du chercheur, le type de données utilisées, et la question à laquelle elle répond.

La recherche qualitative se déroule en milieu naturel, et les données de contexte sont utilisées dans l'interprétation de l'expérience du participant. On sait comment le contexte social, familial, culturel, modifie la compréhension, le vécu et l'expression de la souffrance psychique (Devereux, 1972; Moro, De la Noë, & Mouchenik, 2006). D'ailleurs, beaucoup de cliniciens utilisent peu les données de la recherche clinique dans leur pratique quotidienne, qu'ils jugent éloignées des préoccupations cliniques, et inapplicables aux situations singulières qu'ils rencontrent (Goering et al., 2008). La grande force de la recherche qualitative est ici sa proximité avec de « *vrais gens dans de vraies situations, en proie avec les problèmes de leur quotidien* » (Goering et al., 2008, p. 146). Cette proximité est celle des cliniciens qui suivent au quotidien des patients. Clinique et recherche qualitative partagent la même perspective sur le sujet. Le contexte social est exemplaire de cette réalité clinique : les participants dans des situations sociales complexes sont souvent exclus des études quantitatives (parfois dans les critères d'inclusion, mais surtout de par leur difficulté à investir un processus de recherche dans son entièreté). Ces mêmes patients sont souvent les principaux protagonistes des recherches qualitatives, la complexité des situations étant souvent synonyme de plus grande richesse et originalité des données (Razafsha et al., 2012).

En recherche qualitative, le sujet est l'expert. L'objectif n'est pas de découvrir la vérité mais de mettre en lumière l'expérience singulière de la réalité du participant afin d'en dégager des propositions théoriques. La perspective du patient prévaut ainsi sur les conceptions du chercheur (Whitley & Crawford, 2005). L'importance laissée à la réalité du participant fait écho à l'importance donnée en clinique à la réalité du patient. L'expérience délirante d'un patient schizophrène ne va ainsi pas être niée ou forclose dans la prise en charge. Dans une autre mesure, il n'est jamais complètement établi qu'un évènement traumatique se traduise par un vécu traumatique et une symptomatologie post-traumatique chez un patient. C'est la rencontre de l'évènement et de la fragilité individuelle qui peut se traduire par l'expression de symptômes de souffrance

psychique. Mais plus encore, la perception ontologique du monde par le participant modifie l'évènement traumatique en lui-même. Si l'on prend l'exemple d'un accident de train, vécu comme traumatique par deux personnes, l'une ayant baigné dans culture occidentale cartésienne, l'autre dans une culture qui fait référence au monde de l'invisible. Pour le cartésien, c'est l'accident de train qui fait trauma et doit être l'objet des soins psychiques. Pour l'animiste, la causalité du trauma devra être cherchée du côté de l'invisible, d'un sort jeté à un membre de la famille, ... L'accident en lui-même devient annexe et n'est plus en lui-même, l'élément central du trauma. La clinique comme la recherche qualitative ont comme principal objet la réalité vécue par le patient. Et le récit d'expérience obtenu à l'aide de méthodes qualitative est complet : contenu en information (ce que c'est), sensation (comment c'est), valeur et signification (ce que ça vaut et ce que ça signifie) (Stanghellini & Ballerini, 2008).

L'engagement du chercheur et de sa subjectivité dans la recherche qualitative est une position tout à fait originale : en recherche classique, lorsqu'il est considéré, le chercheur est le plus souvent un élément extérieur et neutre sur le phénomène étudié ; ou encore il est le technicien permettant d'organiser le cadre nécessaire à la mesure. En qualitatif, au contraire, le chercheur participe activement : il s'engage dans le processus interprétatif, participe à la co-construction de la réalité du participant (Goering et al., 2008; Razafsha et al., 2012). La connaissance prend forme dans l'interaction chercheur-participant, et la connaissance nait des significations données à la réalité (St-Cyr Tribble & Saintonge, 1999). La subjectivité du chercheur imprègne chaque étape de la recherche : du choix des participants, à l'interprétation des données verbales et non-verbales issues de l'observation du participant ; de la déconstruction des données jusqu'à leur réorganisation synthétique. Il s'agit de l'ensemble des éléments propre au chercheur qui vont participer à la construction des significations données à la réalité. Ce positionnement du chercheur n'est pas tout à fait étranger au psychiatre clinicien, qui, comme psychothérapeute, est investi par le patient, s'assure de la mise en place du cadre relationnel, de l'alliance, donne un peu de lui dans chaque prise en charge. C'est d'ailleurs l'important résultat d'une étude qualitative qui proposait à des patients suivis en psychothérapie d'évaluer subjectivement les éléments aidants de la thérapie

(Elliott, 2008) : parmi les éléments importants, les patients décrivent comment ils se construisent une image mentale de leur thérapeute qu'ils gardent en tête et utilisent dans leur quotidien entre les consultations et à l'issue de la thérapie. De même que le patient est l'expert de sa souffrance, le participant est l'expert de son expérience. De même que le clinicien assiste le patient dans la construction de sens à sa souffrance, le chercheur qualitativiste assiste le participant dans la construction de sens à son expérience. On peut ainsi rapprocher l'utilisation de la subjectivité dans la recherche qualitative à l'utilisation des éléments de contre-transfert en clinique et en recherche. Nous entendons par contre-transfert « la somme de toutes [les] réactions explicites et implicites [du clinicien-chercheur] par rapport à son objet de recherche et aux angoisses que cet objet suscite chez lui au niveau du choix de cet objet, de la manière de l'observer, de le penser, de l'analyser » (Moro, 1992, p. 75‑77; Devereux, 2012, p. 74‑81). La subjectivité est centrale en recherche qualitative, tout comme le contre-transfert et son étude pour « toute science du comportement » selon Devereux (Devereux, 2012, p. 15‑16).

Les données cliniques et qualitatives sont de même ordre : pour évaluer la souffrance et les symptômes d'un patient, le clinicien va effectuer une étude qualitative de son observation ainsi que du récit du patient qu'il traite. Les données qualitatives sont issues d'observations et de récits de participants. Le récit narratif est au cœur des prises en charge comme le rappellent Falissard et coll. (2013), du *traitement moral* de Pinel à la *talking cure* Freud (Falissard et al., 2013). Même si les mots et les chiffres peuvent être réconciliés dans certaines constructions expérimentales (Cohen, Milman, Venturyera, & Falissard, 2011), la recherche qualitative permet d'accéder et d'analyser le récit narratif de manière directe, en situation.

La question, enfin, à laquelle cherche à répondre la recherche qualitative, est celle du pourquoi, du comment. Donner du sens, c'est également le quotidien du psychiatre clinicien : construire un sens à ce qui nous arrive apaise, soulage, même si cela ne guérit pas. On voit combien, dans le psycho-traumatisme, l'impossibilité de penser l'impensable, la rupture dans le récit narratif, l'incapacité de donner du sens à ce qui s'est passé torture nos patients

(Mouchenik, Baubet, & Moro, 2012). On le constate au quotidien dans les prises en charge de familles migrantes en consultations transculturelles : la perte de continuité entre cadre culturel interne et externe rend difficile le recours aux significations culturelles d'origine, ce qui est générateur de souffrance (Moro, 2004). Cela est pourtant également vrai au quotidien des prises en charge médicales, et la position de *technicien* du médecin somaticien spécialiste qui traite le trouble en laissant peu de place au sens est aujourd'hui de plus en plus remise en question, notamment devant l'échec de certaines prises en charge (Cleemput & Kesteloot, 2002). Le sens donné aux symptômes occupe une place centrale dans tous les soins ; il est également au cœur de la recherche qualitative.

2.1.3. Quelle recherche qualitative en psychiatrie de l'adolescent ?

Si le champ des possibles en qualitatif est aussi vaste que l'esprit humain peut le penser, il est important de délimiter les principales utilisations envisageables en recherche en psychiatrie. Brown et Lloyd (2001) en proposent quatre. Durant les phases exploratoires des projets de recherche, les recherches qualitatives permettent de préciser la question de recherche, aident à la conceptualisation et à la génération d'hypothèses. Après une phase quantitative, l'étape qualitative apporte des précisions permettant d'enrichir les interprétations. En particulier, les études qualitatives sont importantes pour identifier et comprendre les cas déviants et les résultats anormaux. Les protocoles cliniques sont également étudiables à l'aide d'études qualitatives : l'intérêt réside alors dans l'analyse des problèmes et de leurs résolutions. Enfin, la quatrième cible du qualitatif serait le vécu subjectif des soins (Brown & Lloyd, 2001).

Onze ans plus tard, Razafsha et coll. (2011) reprennent les cibles identifiées par Brown et Lloyd en les complétant. Les phases exploratoires qualitatives telles que décrites plus hauts sont déployées dans des domaines très vastes, investies par des disciplines très biologiques comme la pharmacologie : on parle alors d'études ethnopharmacologiques. Pour les auteurs, la définition de nouveaux critères diagnostiques doit passer par des études qualitatives préliminaires. Les études qualitatives sur les perceptions et croyances par rapport au soin et à la

maladie permettent des avancées majeures dans la compréhension des mécanismes à l'oeuvre. Razafsha et coll. proposent encore deux cibles importantes du qualitatif : les études traitant de questions socialement sensibles ; ainsi que les situations où l'on cherche à comprendre les freins à l'inclusion d'un un essai contrôlé randomisé (Razafsha et al., 2012).

Goering et coll (2008) précisent également l'importance du qualitatif dans l'étude du vécu subjectif du soin. Ces études mettent en lumière les forces et les limites des interventions, la désirabilité du soin, les attentes des patients et les écarts entre leurs objectifs et les objectifs du soin. (Goering et al., 2008)

Au total, Stanghellini et Ballerini (2008) résument les principales indications qualitatives en psychiatrie :

- la formulation d'hypothèses et la conception d'outils de mesure (études exploratoires)
- la confirmation de la pertinence en contexte clinique de conceptions psychopathologiques obtenues en laboratoire
- l'évaluation en contexte clinique de dysfonctions cognitives et leur lien avec la pathologie
- la proposition de nouvelles perspectives sur des phénomènes cliniques déjà étudiées par la recherche classique
- la clarification du rôle de certaines variables d'un phénomène lorsque la recherche classique obtient des résultats inconsistants (Stanghellini & Ballerini, 2008)

La clinique de l'adolescent est une discipline jeune, et les études jusqu'à une période récente étaient d'avantage des études *sur* les adolescents que des études *avec* les adolescents (Bassett, 2010; Rich & Ginsburg, 1999). Les nombreuses réflexions sur la place du patient dans le soin n'ont pas épargné le soin pédiatrique et pédopsychiatrique (Beresford & Sloper, 2003; Tates & Meeuwesen, 2001; Tates, Meeuwesen, Elbers, & Bensing, 2002; van Staa & On Your Own Feet Research Group, 2011), autorisant par là-même le développement d'études offrant une place active aux enfants et qui leur donne la parole (Bassett, 2010; Grover, 2004). Les études qualitatives sont les méthodes de choix dans cet exercice : la flexibilité de leur design, la co-construction de

l'interprétation permettent de limiter l'influence des logiques du chercheur et la hiérarchisation de la pensée. L'utilisation de médiateurs (notamment l'image, la vidéo) permet le plus souvent un grand investissement du jeune participant (Drew, Duncan, & Sawyer, 2010).

Comme le rappellent Rich et Ginsburg (1999), l'adolescence est le temps de l'acte, et l'importance des choix comportementaux durant cette période en fait un objet de choix pour la recherche qualitative. L'adolescence possède ses codes, ses valeurs, son organisation sociale, ses cultures et son langage propre. « *Ce qu'un adulte considère comme un comportement à risque peut prendre un sens totalement différent chez un adolescent.* » (Rich & Ginsburg, 1999). De plus, l'influence réciproque de l'environnement sur le psychisme est extrêmement forte à l'adolescence (Brusset, 2004). La porosité aux autres, aux idées, au groupe social, est plus importante que dans d'autres périodes de la vie. Les méthodes qualitatives sont utiles pour mettre en lien contexte et expérience vécue.

Enfin, c'est dans l'expérience subjective du soin que la recherche peut également apporter énormément au soin aux enfants et adolescents. Les jeunes ont un rapport à la souffrance, à la maladie, et aux prises en charge parfois très éloigné de celui des adultes. L'étude fine des spécificités de ces aspects doit permettre de proposer des soins plus adaptés aux préoccupations et aux attentes de cette population (Lachal et al., 2012; Rich & Ginsburg, 1999).

2.2. Le contexte des métasynthèses

2.2.1. Pourquoi des synthèses qualitatives ?

Le nombre de travaux qualitatifs progresse rapidement en médecine et en psychiatrie (Bilderbeck et al., 2014; Crawford et al., 2008; Dinos et al., 2004; Oldershaw, Richards, Simic, & Schmidt, 2008; Perkins et al., 2004; J. Price et al., 2009; Serpell et al., 1999; Sinclair, 2005; Winn, Perkins, Murray, Murphy, & Schmidt, 2004). Mais la littérature qualitative pose plusieurs problèmes, parfois très proches des problèmes rencontrées avec des protocoles quantitatifs :

- elles sont mal indexées et difficiles à trouver en pratique. Le thesaurus term Qualitative Method de PubMed n'existe que depuis 2002 et il est globalement boudé par les auteurs (Booth, 2016c; Ring, 2011). Les méthodes sont multiples et les mots clés qui servent aujourd'hui à signifier l'observation ou le recueil d'expérience sont multiples : expérience, attitudes, croyances, regards, comportements, émotions, vécu … Le mot clé libre *qualitative* ramène d'avantage d'études sur la qualité que d'études qualitatives. Globalement, les auteurs s'accordent à dire qu'à l'issue d'une recherche systématique protocolisée, 1 à 5% des études sont finalement inclues dans la métasynthèse (Shaw et al., 2004). Ce problème s'est déjà posé il y a quelques années pour les essais contrôlés randomisés : à la fin des années 1990, une étude avait montré que seuls 30 à 80% des ECRs étaient identifiés lors d'une recherche (Dickersin, Scherer, & Lefebvre, 1994).
- Elles sont de plus en plus nombreuses et il est difficile de s'informer sur la totalité des connaissances qualitatives publiées au quotidien (Hannes et al., 2013; Toye et al., 2014).
- Les méthodes sont multiples et peu connues du public de cliniciens à qui elles sont destinées. L'évaluation de leur qualité et de leur transférabilité n'est ainsi pas toujours aisée.
- Elles sont souvent isolées, et participent peu au mouvement de *l'Evidence-Based Medicine* (Evans & Pearson, 2001; J. Thomas & Harden, 2008; Zimmer, 2006).

Les synthèses qualitatives permettent de répondre en partie à ces limites. Elles proposent de rassembler plusieurs études dont elles évaluent la qualité. Elles résument les concepts clés de chaque étude dans les résultats et apportent un niveau interprétatif supplémentaire, facilitent la transférabilité des données et proposent le plus souvent des applications cliniques ou théoriques directes.

2.2.2. Bref historique du développement des méthodes de synthèse de la littérature qualitative

L'origine des métasynthèses qualitatives remonte à Noblit et Hare. Ces deux auteurs posent en 1988 les premières pierres d'une méthode qu'ils baptisent *Meta-ethnography*. La Meta-ethnography est la base de toutes les méthodes actuelles de synthèse d'études qualitative (B L Paterson, 2012). Leur objectif est de structurer une méthode de synthèse permettant d'articuler et de proposer une interprétation globale d'un petit nombre de recherches ethnographiques publiées dans des livres. Ils développent ainsi trois types de synthèses : les *transpositions réciproques* (reciprocal translations) lorsque les résultats des études sont proches, les *synthèses infirmatives* (refutational synthesis) lorsque les études s'infirmes les unes avec les autres, et les *synthèses argumentatives* (line-of-argument synthesis) lorsque les études se complètent pour construire un raisonnement (Lee et al., 2014).

Les deux principaux éléments de la métasynthèse sont ainsi définis :

- la *translation* est au cœur de tout exercice de métasynthèse. Il s'agit de l'exercice qui consiste à prendre les concepts clés d'une étude et les identifier dans une autre étude où ils sont exprimés d'une façon différente (J. Thomas & Harden, 2008)
- Le *line-of-argument* est la construction obtenue à l'issue de l'exercice de translation. Il s'agit d'un raisonnement scientifique, proposant une interprétation originale à partir des concepts clés extraits de chaque étude et transposés d'études en études, soit un troisième niveau d'interprétation (Atkins et al., 2008).

Noblit et Hare proposent une méthode en sept étapes itératives (Noblit & Hare, 1988), mais elle est peu utilisée jusqu'au milieu des années 1990, ou de nombreux auteurs s'en emparent et la développent. C'est à cette période que se constitue le CQIM group, branche qualitative de la Cochrane Collaboration (Hannes et al., 2013). Des réflexions épistémologiques et méthodologiques sont entreprises et différents courants se dessinent petit à petit.

Pour comprendre ces différents courants, on peut les distinguer en méthodes de revue plus intégratives et plus interprétatives : les revues intégratives proposent de regrouper ou d'agréger les données des différentes études, tandis que les revues interprétatives proposent une approche émique où le raisonnement et la construction des résultats est interprétative et inductive (Noblit & Hare, 1988). Toutefois, cette distinction binaire est trop schématique, et certains auteurs proposent une catégorisation en quatre types de méthodes (Campbell et al., 2011) :

- les méthodes dites *agrégatives* ou *numériques*. Ce sont les méthodes les plus proches des études quantitatives. Le codage analytique systématique des études est ensuite regroupé pour permettre une analyse statistique et la mise en évidence de liens de causalité. Le plus souvent, les études quantitatives sont associées aux études qualitatives dans la synthèse. Les principales méthodes agrégatives sont le *Case Survey Method* (Yin, 2013), les *Bayesian Methods* (Roberts, Dixon-Woods, Fitzpatrick, Abrams, & Jones, 2002) et la *Metasummary* (Sandelowski, Barroso, & Voils, 2007).
- les méthodes dites *narratives* ou *comparatives*. Le codage analytique est ici aussi agrégé mais dans une démarche de comparaison et de réplication des résultats dans le but d'obtenir une synthèse narrative plus que numérique. La production de nouvelles perspectives et le développement conceptuel est possible, mais ce n'est pas le but ultime de la revue. Il est important ici de distinguer les *Narratives Reviews*, qui proposent uniquement un résumé des principaux résultats de la littérature, des *Narrative Synthesis*, qui reposent sur des techniques d'analyse rigoureuses et systématiques (codage, le plus souvent thématique, et interprétation) et proposent une synthèse analytique ou encore un troisième niveau analytique (Zimmer, 2006). Les principales méthodes narratives sont la *Narrative Synthesis* (Popay et al., 2006), la *Thematic Synthesis* (J. Thomas & Harden, 2008), *la Meta-Narrative Synthesis* (Greenhalgh et al., 2005) et la *Framework Synthesis* (Brunton & EPPI-Centre, 2006).

- Les méthodes dites *interprétatives* ou *développementales*. L'objectif est de construire un cadre conceptuel original complet, une nouvelle théorie. La méthode d'analyse est systématique, inductive, mais le niveau interprétatif est plus important puisqu'il s'agit de proposer une nouvelle théorisation du phénomène. La *Meta-Ethnography* (Noblit & Hare, 1988) fait bien entendu partie de ces méthodes, ainsi que de nombreuses autres méthodes dérivées dont les principales sont la *Meta-Study* (Barbara L. Paterson, 2001), la *Critical Interpretive Synthesis* (Dixon-Woods et al., 2006), la *Realist Synthesis* (Pawson, 2002), et la *Grounded Theory Synthesis* (Kearney, 1998).
- Enfin, les méthodes dites *de seconde analyse des données*. Dans les trois premières catégories de méthodes, le reviewer analyse l'article qui contient à la fois les données des participants et les interprétations des chercheurs. Ici, le travail se concentre uniquement sur les données des études princeps. Il s'agit de proposer une nouvelle analyse de plusieurs sets de données afin d'en dégager de nouvelles perspectives. Cette procédure très chronophage est aujourd'hui peu utilisée (Bloor & MacIntosh, 1990).

Une autre manière de classer les différentes méthodes s'effectue à partir de leurs conceptions épistémologiques. Spencer et coll. (2003) différencie cinq courants épistémologiques (Barnett-Page & Thomas, 2009; Spencer, Ritchie, Lewis, & Dillon, 2003):

- *L'idéalisme subjectif* : il n'existe pas de réalité partageable indépendante des multiples constructions humaines. On peut y associer la *Meta-Narrative Synthesis*, la *Critical interpretive Synthesis*, et la *Meta-Study.*
- *L'idéalisme objectif* : le monde est peuplé de conceptions subjectives partageables collectivement. Y sont associées la *Meta-Ethnography,* la *Grounded Theory Synthesis* .
- *Le réalisme critique* : la connaissance sur la réalité est médiée par nos perceptions et croyances (*Thematic Synthesis, Framework Synthesis*).

- *Le réalisme scientifique* : la connaissance peu s'approcher d'une réalité externe (*Case Survey Method, Bayesian Methods, Metasummary*).
- *Le réalisme naïf* : la réalité existe indépendamment des constructions humaines et peu s'appréhender directement.

En parallèle des réflexions épistémologique, le nombre de métasynthèses n'a cessé de progresser dans le domaine médical. Si le nombre de publications annuelles est de l'ordre d'une dizaine entre 1995 et 2000, il grimpe rapidement pour atteindre une centaine de publications par an en 2010 (Hannes et al., 2013; Hannes & Macaitis, 2012). Tous les domaines de la santé sont aujourd'hui concernés. Parallèlement, le type de méthode utilisé tend à s'uniformiser autour de cinq principaux courants : la *Meta-Ethnography*, la *Thematic Synthesis*, la *Critical Interpretive Synthesis*, la *Narrative Synthesis*, et la *Meta-Study* (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

Depuis les années 2000, d'importantes métasynthèses sont ainsi publiées régulièrement dans les grandes revues internationales (Marshall, Wolfe, & McKevitt, 2012; Mcewan, Espie, & Metcalfe, 2004; Mills et al., 2006; Morton, Tong, Howard, Snelling, & Webster, 2010; Munro et al., 2007; Smith, Pope, & Botha, 2005; Tong, Lowe, Sainsbury, & Craig, 2008; Tong, Morton, Howard, & Craig, 2009). La première publication de la Cochrane Database a lieu en 2013 (Gülmezoglu, Chandler, Shepperd, & Pantoja, 2013). Un recensement récent évoque le chiffre de 40 à 70 métasynthèse publiée chaque mois en 2015, dans de nombreuses disciplines (Booth, 2016c). Les guides et protocoles méthodologiques se multiplient (Booth, 2016a; Booth et al., 2016; Hannes & Lockwood, 2012; Noyes, Popay, Pearson, Hannes, & Booth, 2011b; Ring, 2011; The Joanna Briggs Institute, 2008) et sont également publiés dans les grandes revues internationales (Lewin et al., 2015; Melendez-Torres et al., 2015).

Pourtant, peu de publications s'intéressent à la psychiatrie. Certains équipes de soignants, de psychologues et de sociologues ont proposé des travaux s'intéressant aux soins primaires (Barley, Murray, Walters, & Tylee, 2011; Finfgeld-Connett, 2009; Khan, Bower, & Rogers, 2007; Knowles et al., 2014), à la

gestion de la violence dans le soin (O. Price, Baker, Bee, & Lovell, 2015), aux interventions en e-santé (Daker-White & Rogers, 2013), ou encore à la place des familles dans le soin (Cairns, Reid, & Murray, 2014). A notre connaissance, une seule étude a été menée par une équipe de psychiatres, sur la signification de l'anorexie mentale chez les patients (Espíndola & Blay, 2009).

2.2.3. Quelles méthodes en recherche psychiatrique ?

Si la métasynthèse est mieux codifiée et de plus en plus utilisée, tout reste à faire en recherche psychiatrique. En effet, les auteurs s'entendent pour affirmer que la méthode choisie doit être adaptée aux positions épistémologiques de l'équipe de recherche, au contexte étudié ainsi qu'aux objectifs de l'étude (Ring, 2011). Il parait donc indispensable de préciser un ou plusieurs types de méthode de synthèse qui puisse s'appliquer au champ de la psychiatrie. C'est cet important travail que nous proposons d'initier dans notre thèse. Sans remettre en question les importants travaux de nos collègues soignants, psychologues et sociologues, il apparait essentiel et complémentaire de proposer des métasynthèses adoptant la perspective des psychiatres et pédopsychiatres sur le soin psychique. Ceci doit permettre un accroissement des connaissances sur la souffrance et le soin psychique, mais également des applications thérapeutiques importantes.

3. Objectifs

Nous proposons dans ce travail de thèse de construire une méthode d'analyse de la littérature qualitative adaptée au champ du soin psychique de l'adolescent. Notre travail repose sur la littérature existante dans le domaine des métasynthèses. Il est à la fois théorique – réflexions épistémologiques et méthodologiques sur la métasynthèse dans le champ du soin psychique – et pratique – la construction de la méthode est réalisée à l'aide de mise en pratique avec des métasynthèses dans le champ du soin psychique de l'adolescent.

Au total, l'objectif principal de notre travail est le suivant :

- Définir une méthode de synthèse de la littérature qualitative adaptée au domaine du soin psychique de l'adolescent, rigoureuse, fiable et simple à transposer et à enseigner.

Les objectifs secondaires sont :

- Faire l'état des lieux des méthodes existantes dans le domaine de la métasynthèse appliquée au champ de la recherche médicale
- Effectuer des revues de littérature dans deux thématiques appartenant au champ du soin psychique de l'adolescent.

METHODE

Notre méthode est exploratoire et systématique. Elle s'inspire de la circularité de l'analyse proposée en recherche qualitative. Ici, les allers retours seront incessants entre les données de la littérature, la construction théorique de notre méthode et son application pratique.

Le déroulement est le suivant :

1. Choix d'une thématique familière entrant dans le champ des soins psychiques à l'adolescence

Le travail de métasynthèse doit être réalisé par une équipe dont certains membres possèdent une bonne connaissance de la thématique (Atkins et al., 2008). Booth et coll. (2016) précisent que l'expertise « *requires more than simply 'does our review team possess the technical expertise to carry the review?'* » Le niveau d'expertise doit être suffisant dans la discipline, la méthode, et les perspectives envisagées (Booth et al., 2016). Ceci permet d'assurer de concentrer la métasynthèse sur les problèmes qui se posent en clinique et pour nos patients. Nous avons ainsi choisi deux thématiques que nous connaissons bien sur le plan clinique.

2. Exploration phénoménologique de la thématique par une étude qualitative

Nous proposons d'ajouter cette étape préalable supplémentaire. Avant d'initier la métasynthèse, nous explorons systématiquement la thématique à l'aide d'une étude qualitative (Lachal et al., 2012; Orri et al., 2014). Cela permet de compléter la perspective clinique que nous maitrisons par une perspective phénoménologique complémentaire. Nous pouvons ainsi envisager les enjeux de soins sous des angles complexes et complémentaires. Cette étape n'est jamais inscrite de manière systématique dans le déroulement de la métasynthèse, même si elle est implicite : les auteurs s'accordent à dire que l'équipe de recherche doit être composée de spécialistes de la question clinique comme de spécialistes de la démarche qualitative.

3. Construction d'un outil méthodologique de métasynthèse adapté à la thématique

Cette construction s'effectue après consultation de la littérature méthodologique dans le champ étudié. Des réflexions en groupe de recherche permettent de définir les différentes étapes. Comme dans toute étude qualitative, le protocole initial n'est jamais rigide et il évolue au cours de la construction. Cette étape est donc intimement liée aux autres étapes.

4. Réalisation de la métasynthèse dans la thématique étudiée

Une métasynthèse est réalisée dans la thématique choisie, en observant le protocole méthodologique établi à ce moment de l'étude. Le protocole est réalisé et les limites rencontrées durant la réalisation de ce travail sont discutées en équipe.

5. Etude des limites de la méthode et réexamen de la méthode à la lumière de la pratique

L'étape précédente permet de mettre en lumière les limites du protocole de métasynthèse. Ces limites sont discutées pendant et à l'issue du travail de métasynthèse, et des solutions sont recherchées dans la littérature.

Nous proposons de réaliser deux fois ce protocole. Ceci doit permettre de préciser les différents points qui pourraient poser problème et de proposer une méthode rigoureuse et aboutie.

Pour des raisons pratiques de nécessité de publication scientifique, le manuscrit n'est pas organisé selon ce développement. Nous présenterons dans les deux premières études les deux métasynthèses publiées. Le troisième article présentera le détail de la méthode obtenue, la synthèse des données de la littérature, ainsi qu'une discussion des limites de la méthode. Les limites seront également discutées à l'issue de la présentation des trois articles.

RESULTATS

Article 1 - Une métasynthèse des perceptions des enfants, des adolescents, des parents et des soignants sur l'obésité des jeunes

Le premier article est une métasynthèse dans le champ de l'obésité de l'enfant et de l'adolescent. Il a été publié en anglais en mai 2013 dans la revue *Obesity Reviews* (revue indexée dans Medline, impact factor à 7,51).

L'obésité de l'enfant et de l'adolescent est un sujet clinique que nous connaissons bien. Nous prenons quotidiennement en charge des adolescents obèses et leur famille, en particulier les situations complexes avec une souffrance psychique et des comorbidités associées. Nous avons par ailleurs déjà exploré la question de l'obésité de l'adolescent avec une perspective phénoménologique au cours d'une étude qualitative en 2012 (Lachal et al., 2012).

A la suite de ces premiers travaux, nous avons décidé d'initier une revue de littérature qualitative interrogeant les enfants et adolescents, leurs parents, et les soignants qui les prennent en charge. Nous avons sélectionné de manière systématique les articles qualitatifs traitant de l'obésité de l'enfant et de l'adolescent dans cinq bases de données numériques, à l'aide de mots clés libres. Sur le plan méthodologique, nous nous sommes inspirés de la méthode décrite par Atkins et coll. (2008) et de la métasynthèse publiée par Pocock et coll. (2010) (Atkins et al., 2008; Pocock et al., 2010). Atkins et coll. décrivent une méthode en sept étapes qui va de la définition de la question jusqu'à l'écriture de la synthèse. Il s'agit d'une méthode proche de la Meta-Ethnography de Noblit et Hare (Noblit & Hare, 1988). La métasynthèse publiée par Pocock et coll. en 2010 traite des perceptions parentales de l'obésité de l'enfant. Nous avons appliqué une partie de la démarche de cette équipe, notamment sur le choix de l'outil d'évaluation de la qualité des études incluses (Spencer et al., 2003). Nous avons enfin choisi, comme préconisé dans la littérature médicale, d'effectuer la recherche et l'inclusion systématique des articles sur plusieurs bases de données numériques. Au final, notre méthode est donc une construction inspirée de différentes méthodes ayant fait leurs preuves en ce qui concerne la thématique choisie.

L'analyse thématique s'organise autour de trois axes d'expérience communs aux trois groupes de participants (les enfants, les parents et les soignants) : Voir et se voir qui réunit les questions de la représentation de soi et de l'autre obèse, de la prise de conscience et du diagnostic ; Comprendre et se comprendre, où l'objectif est de tenter de donner du sens au trouble ; et enfin Traiter et se traiter, où l'enjeu est double, celui de l'appréhension globale de la démarche de soin d'une part, et celui de l'évaluation subjective de chaque thérapeutique spécifique d'autre part. La proposition centrale aux expériences des différents participants est celle d'une absence de mots dans la relation parents-enfants-médecin. Chacun s'empêche de dire l'obésité par peur des conséquences (générer des troubles alimentaires, de la souffrance psychologique et du rejet, perdre l'alliance thérapeutique). Cette absence de mot est responsable d'un retard diagnostic qui gêne la prise en charge et grève le pronostic. L'étude propose des pistes d'aménagement clinique –proposer un espace d'échange des représentations de l'obésité au sein de la consultation thérapeutique en y associant les parents– et des recommandations pour les soignants et les chercheurs –partage des informations et des perspectives individuelles sur l'obésité.

Qualitative studies among obese children and adolescents: a systematic review of the literature

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Title: Qualitative studies among obese children and adolescents: a systematic review of the literature

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Abstract

Childhood obesity is a complex condition involving medical, social, moral and cultural issues. Qualitative approaches are of great value in understanding this complexity. This meta-synthesis of 45 qualitative studies deals specifically with the issue of obesity in children and adolescents from different perspectives — those of obese children and adolescents, of parents, and of health professionals providing support to the family. Our aim is to obtain a coherent view of child and adolescent obesity, focused on clinical and personal experience. The themes derived from the synthesis process fall under three main axes: "Seeing others, seeing oneself", "Understanding others, understanding oneself", and "Treating others, treating oneself". It emerges that participants in all 3 groups had equal difficulty in perceiving and labelling obesity, due mainly to their lack of any real

common ground. The insufficiency of shared representations destabilises the therapeutic relationship and its construction: an important issue in the doctor-child-parent relationship in this context is the need to exchange their viewpoints of obesity. Health workers may also expand their understanding of obesity by incorporating the personal experiences of obese children and their parents in order to match treatment plans to their needs and expectations.

Key words

Qualitative research, meta-synthesis, children, obesity, family, psychology

Background

The prevalence of obesity makes it a major public health concern — 500 million people are thought to be affected according to the World Health Organisation (WHO) (1). Obesity also affects children, and the number of obese children is very high all over the world (2,3). For instance, the prevalence of childhood obesity in the USA is estimated at 11.9% (4). The consequences of obesity in childhood — which can be orthopaedic, neurological, respiratory, hepatic, endocrine, psychiatric and cardiovascular - are well known today (5–7).

Obesity is a complex condition to understand, involving as it does medical, social, moral and cultural issues (8). It can be defined in a variety of ways. Medically it is characterised by a single value, the body mass index (BMI): its cut-off points are the basis today for considering that a health risk exists (1). Socially it is associated with disability and vulnerability and sometimes even hampers social integration. Culturally, representations vary considerably: an obese body is associated with poor health in western countries, while in other regions of the world it can signify power, strength and health (9). Morally, attitudes range from an accusatory viewpoint which sees obesity as the result of a lack of will-power and self-control to a medical viewpoint according to which excessive weight is the consequence of organic disorders that are independent of any form of mental control (10).

The treatments for obesity are being challenged today; despite research showing some positive short-term benefits, there is limited "*information on the long-term outcomes*" (11,12). Recent studies and professional guidelines increasingly stress

the importance of parental involvement in the care process (11–17). Most of these studies point out difficulties in the encounter between healthcare professionals, parents and the obese child (18,19). We sought to explore the issues related to child obesity from these three perspectives, and to examine elements that facilitate and barriers that can jeopardize treatment success.

A qualitative approach can help to shed light on the complex nature of obesity. Qualitative studies are increasingly used in medical research (20,21). They rely on the analysis of narrative material derived from interviews, focus groups, written documents, videos, photographs and observations. They posit the participant as the "expert" and often enable researchers to collect original and valuable material. An in-depth analysis of the subject-matter that takes the setting into account can be performed (22), and specific quaity criteria to assess its validity and rigour must be met (23).

Several qualitative studies in medical and psychological areas have explored the perspectives of young obese individuals, their parents, and more recently their health care providers, to elicit their beliefs about and representations of obesity and its treatment, as well as to identify facilitators and barriers to change. In particular, findings about the involvement of the family in the treatment process show that adolescents often consider parents as the main driving force pushing change (11). These studies emphasize the importance today of considering the subjective perceptions of children and their families at the core of treatment strategies (11–17). In recent years, only two literature reviews focusing on parental perceptions of child obesity have been published. The larger one, by Pocock et al (2010), aimed to illustrate the factors that parents believe are involved in the prevention of obesity (24). The second, narrower in scope, explored parental representations of childhood obesity in a Mexican-American population (25).

The challenge of synthesising qualitative literature is somewhat different from that of the standard reviews and meta-analyses of quantitative research. Quantitative reviews seek to aggregate statistical data from several different studies. In contrast, qualitative meta-syntheses are considered "a type of qualitative study that uses as data the findings from other qualitative studies

linked by the same or related topics" (26). This involves a second level of analysis, in which studies are compared and translated into one another in order to develop an overall concept — often called line-of-argument (27,28). Hence, the aim is not to analyse data, but to develop theory, achieve a higher level of abstraction and a greater scope for generalization, so that qualitative results can be more easily applied to practice.

Aims and Objectives

The present review aims to propose a coherent view of child and adolescent obesity. In order to obtain an integrated description of the subject, we included the perspectives of children and adolescents, parents and health-care professionals. We focused on individual representations of obesity and personal experience of treatment, rather than prevention.

Method

This meta-synthesis is based on the procedure described by Atkins et al (29), adapted from meta-ethnography (27,29). This method makes it possible to include qualitative articles applying various and heterogeneous methods of analysis. The presentation of the results is thematic. Our work method used the following steps:

1) Definition of the research question, summarized in the Aims and Objectives

2) Identification and selection of studies

3) Quality assessment of the selected studies

4) Analysis of the articles and identification of themes

5) "Translation" of the themes across studies

6) Synthesis of the translation

7) Expressing the synthesis

Selection of studies (Step 2) (Figure 1)

We conducted a systematic search for qualitative studies specifically devoted to obesity in children and adolescents. Meetings of the QUALIGRAMH working group (Qualitative Group for Research in Adolescent Mental Health, INSERM U

669, Maison des Adolescents, Hôpital Cochin, Paris), composed of specialists in qualitative research and weight-related disorders, defined the study criteria.

The articles were selected only if they met the following criteria:

- used solely qualitative methodology
- specifically concerned obesity in children and adolescents
- interviewed obese children, obese adolescents, parents of obese children or adolescents, or health-care providers for obese children and adolescents
- were published in English, between 1990 and 2011.

Thus the following were excluded:

- studies using quantitative or mixed methodologies
- studies in the general population exploring prevention of obesity or social representations of obesity in children and adolescents
- studies concerning children with an organic disease, or meeting DSM-IV-TR diagnostic criteria for eating disorders.

The study was conducted from August to December 2011. An initial search identified a selection of articles, from which we collected key words. The research group drew up a list of 48 key-words, free-text terms relating to obesity in children and adolescents and qualitative research, as recommended in the literature (30,31). It also compiled a list of databases indexing qualitative studies in the fields of medicine, sociology and psychology (29,30,32) (Table 1).

A screening procedure identified the period 1990 to 2011 as the period in which most of the qualitative studies on obesity appeared. This topic became a major subject of concern in the 1990s in the western world, and many qualitative studies were performed. We therefore decided to restrict the search to this period.

In all 6453 references were obtained, of which 4322 remained after removal of duplicates (Table 2). The two main authors (JL and ARL) screened all titles and abstracts, according to the relevance of their theme and methodology. If the abstract was not sufficient, the full text was read. Disagreements were resolved during working group meetings. Full texts of potentially relevant articles were

then examined, and a second selection was performed. After removal of studies that did not meet the criteria defined above, 43 articles remained. Scanning the reference lists for more potentially relevant articles provided 2 more articles. In all, the review finally included 45 studies, around 1% of the articles screened, which is consistent with the findings of other such meta-syntheses (29–31) (Table 3).

These studies can be classified according to who participated: 14 interviewed children and adolescents, 15 only parents, 7 parents and children, and sometimes the wider family, and 8 interviewed health professionals, including general practitioners (GPs), paediatricians, nutritionists, dieticians, nurses, and directors of obesity clinics. Finally one study interviewed all three groups. The detail of population and method can be found in Table 3. As participants were from varied countries and ethnic origins, some cultural aspects have been pointed out in the results. However, they are too limited to propose an overall view of how the cultural context plays out in participants' statements.

Evaluation of article quality (Step 3)

There are hundreds of methodological tools for the assessment of qualitative articles (24). The evaluation of quality is nevertheless necessary to enable discussion of the studies and to ascertain the value and integrity of the data used, so as to eliminate studies whose results are not sufficiently rigorous. The working group chose to use a tool adapted from the Quality Framework proposed by Spencer et al. (33), which has proved effective in several qualitative reviews, in particular about childhood obesity (24,34). Table 4 summarizes the quality evaluation criteria *(Table 4).*

Data analysis

We followed the procedure described by Atkins et al. (29) to analyse the data. The analysis included a careful reading of the full articles, as well as their titles and abstracts (35). The process consisted in carefully reading and re-reading each study. One researcher (JL) extracted the formal characteristics of the studies, while data extraction and analysis was independently performed by three researchers (JL, ARL and MO) and then compared during meetings. We used thematic analysis to inductively develop categories from the first-order

themes identified in these studies. Afterwards, the translation work involved comparing themes across papers to match themes from one paper with those from another and ensure that each key theme captured similar themes from different papers (Step 5). Finally, we ordered translation results in a framework containing three headings (Step 6). The last step consisted in expressing the synthesis in a useful form (Step 7)

This process led not to a summary of the different studies included, but to an interpretation of the articles that enabled us to "produce a higher order of interpretations and generate theories from multiple studies" (29). Research meetings were held regularly to discuss the results obtained. The triangulation of sources – meta-analysis does this by definition – and the triangulation of reviewers made possible a high level of rigour (23,36) in the results.

Results

Quality assessment

Notwithstanding some minor limitations, our evaluation found that the quality of the studies was good on the whole (Table 4, Table 5). Limitations included: little or no presentation of the sampling procedure; lack of clear-cut criteria for generalising the results; an inadequate or incomplete description of the analysis method and, finally, in eleven studies, no reference to ethical approval, although the papers were all published in journals requiring this condition to be met. No study was excluded from the analysis on the basis of this evaluation. The original authors of the meta-ethnographic approach report that poorer quality studies tend to contribute less to the synthesis (27,29,34), which becomes “weighted towards the finding of the better quality studies” (37). Further, there is no consensus on the role of quality criteria and how they should be applied, in particular for systematic reviews (see more (24,29,38)).

Thematic analysis

The thematic analysis of the literature enabled us to identify the three axes of experience common to the three groups of protagonists: child, parents, and health-care providers. We labelled the first “seeing others, seeing oneself”; it involved representation of the obese other and the obese self. Both the processes by which participants define obesity and their awareness of it as a problem were

taken into account. Differences and similarities between the views of children, parents and professionals are shown. The second, “understanding others, understanding oneself”, describes the meaning-making process in obesity and overweight, how each participant tried to explain the origin of the condition, and the factors perceived to be related to it. Finally, “treating others, treating oneself” is concerned with 2 aspects: overall understanding of the provision of care and subjective evaluation of the care. Table 6 describes the organization of results and presents some representative excerpts.

Seeing others, seeing oneself

This axis concerns the process whereby the child or adolescent, the parent, or the healthcare professional becomes aware of the state of obesity, each constructing his or her own references for recognising it.

Children and adolescents

Children and adolescents’ definitions and awareness of obesity are both based on social-related situations, rather than individual characteristics. Despite the wide variation in the way in which children and adolescents defined both themselves and others as obese, this definition was never related to BMI or other medical-related signs. Instead, they seem to base their definition of obesity on appearance, and their judgment is mainly based on visual aspects, such as ‘sagging skin’ or ‘flabby body’ (39,40). Cultural differences also influenced the definition of obesity: in western cultures obesity is synonymous with bad health, in other cultures, for example in both Iran and Cameroon, it has a positive value, signalling good health, strength and power (9,41).

Awareness, on the other hand, usually emerged in contexts in which adolescents were the object of social disapproval. Children and adolescents frequently reported that they had been taunted or bullied by their peers. In those situations, the predominant consequences were isolation, peer anxiety, low self-confidence, and body dissatisfaction. These findings raise the complex question of the common social representation of obesity that leads both to its definition and to awareness of it as a social problem and thus becomes the reference point for the perception of oneself and others as obese (7-10,15,41–51).

Parents

Becoming aware of their child's obesity seemed to be a complex process for the parents. This was a difficult phase, as it called the quality of their parenting into question. Often parents underestimate or minimize the child's overweight. In some cultural environments (for example in Latino immigrant families in the US, (53)), criteria for obesity may be even rejected (52–55).

Like adolescents, parents use different social markers to diagnose their children's weight problem: clothes size, general appearance, well-being and physical activity, emotional distress, but medical criteria were not mentioned. (48,56–58).

When parents became aware of their child's obesity, the main problem they faced was how to talk with him or her about it, how to address the matter without hurting or annoying the child (8,16,59). Beyond their worry about upsetting the child, however, putting the problem into words is a way of making it "official", and this inevitably leads to self-questioning and to the need for action to solve the problem. It is important to note that the physician was generally seen as an ally in approaching this issue (16,46,60,61).

Healthcare professionals

Among medical personnel, BMI is the official norm for the diagnosis of obesity. They reported, however, that they tend to base their diagnosis on more clinical aspects: general health and, above all, eating behaviour (62–64).

General practitioners were frequently interviewed in the studies, since they are on the front line in diagnosis and care of obesity in children and adolescents. They defined themselves as clinicians who should raise "the issue of the child's weight", and manage "any associated medical problem". However they consider themselves insufficiently skilled in the area of weight loss and diet, which they saw above all as a "family problem" (65).

While professionals detected and diagnosed obesity fairly easily, they reported that they found it hard to talk about weight with patients and parents. These studies showed a variety of obstacles. Some were related to external reasons, such as lack of time, absence of adequate treatments or gold standards; others were related to the patient or family, such as pessimistic views of teenagers'

ability to alter their eating habits. Doubt was also expressed about the ability of families to change, in particular when the parents themselves are obese, difficulty dealing with the situation because of the need to work with the families, the feeling that parents are not aware of their child's obesity problem. Above all they were afraid of breaking their therapeutic ties with the family by tackling the subject of the child's obesity. Clinicians are very aware of the social prejudice towards obesity, the links between nurturing, bonding and caregiving, and the use of food to control relationships. They do not want to upset parents of children, nor weaken the relationship with the family by questioning its functioning. Nor do they want to compromise ties within the family itself. Finally, they are afraid of having to cope with divergent opinions about excess weight, mainly of a cultural nature (8,62,63,65–69).

Understanding others, understanding oneself

This axis of experience demonstrates how each different group understands obesity.

Children and adolescents

Despite the uniqueness of each individual history, a common trend emerged throughout these studies. The main explicative factors that children and adolescents acknowledged in making sense of their condition were external. No one seemed to link obesity to psychological issues or take individual responsibility for it. Various factors were named: genetics, heredity, and God (8,40,41,46). Some different factors were deemed responsible for continued obesity: like the first group, these were always external and the participants passive bystanders: lack of suitable sporting facilities, fear of teasing (14,16,39,48,49,51,52,70,71).

Parents

The theories put forward by parents to explain their child's eating difficulties varied according to the population interviewed, its culture, and its socioeconomic level. It is interesting to note how parents create an original explicative theory from different messages:

- Social and cultural messages (for instance, eating unrestricted quantities of rice in Oceania) (48,52,53,72,73).

- Medical and nutritional messages. Here we find notions involving genetics, slow metabolism, or bad eating habits. These notions appear preponderant in families where the parents themselves are obese. (46,54,55,57,59,74,75).
- Family messages, which evolves from one generation to the next. The family culture influences the way in which obesity is understood: the role of the extended family is taken into account in the transmission of an implicit message that potentially leads to obesity. Parents also consider that their attitudes, including overprotection or lack of control, could be related to their children's overweight and to the efficacy of treatment. (57,74)

Finally, parents cited the role of regulating emotions and stress in their children and also their parental duty to control their children (8,14,46,57,58,60,74).

Healthcare professionals

The aetiological theories put forward by physicians and other healthcare professionals overlapped fairly well on multifactorial medical theories combining heredity and environment (8,16,62–67). However some physicians emphasised other causes of obesity in adolescents: "an unhealthy diet and lack of physical activity... and a lack of family cohesion" (69). The cohesive function of food was also pointed out by physicians, either because it is excessive (fusional family relationships) or in contrast because it is inadequate (family conflict and distended relationships) (16,58,76).

Treating others, treating oneself

Here two themes relating to care were distinguished. The first involved understanding the overall care system: who occupies what position, what role, how each participant sees treatment and decides when it is necessary or appropriate, what mechanisms regulate compliance, rejection and alliance. The second was a subjective evaluation of the main mode of treatment offered, by the young people, their parents, and sometimes health-care professionals.

Overall understanding of the provision of care

Children and adolescents

An initial difference was found between girls and boys about their *"rationale for managing weight"* (71). While for girls the aim is primarily to improve their physical appearance, for boys it is mainly related to better performance in sporting activities and muscular development (46,71). They want moral support providing self-esteem and reassurance. They believe that psychological treatment is most appropriate for their concerns. What must be tackled is not the weight problem or the body, but self-confidence and self-esteem. More concrete support is also sought, such as company in following a diet or exercising. Most of them emphasize that it is important for this support to be stable and long-lasting. Interestingly, mothers are seen as the main drive for change by obese children of both genders (11,14,16,39,40,42,45,49,51,52).

Changes in the level of physical activity appear to be more readily accepted than changes in dietary habits. Those who exercise nonetheless acknowledged some barriers. These were mainly related to their appearance and to the fear of stigmatization: of being humiliated during sports practice, of changing into gym clothes, of being rejected by teams, and of not meeting social norms. Familial barriers were also identified by the participants, such as a lack of family support or involvement in sporting activities. (11,41–43,50,51,71).

Parents

Parents appeared ambivalent in their attitudes to treatment. They are caught between the desire to do something for their child's overweight and the fear of the potential consequences of their action:

- Acting to control their child's eating behaviour is beneficial for preventing the long-term consequences of obesity and for the child's health. But there is also a risk of engendering a loss of self-esteem and even causing bulimic and anorexic behaviours in the child. Finally there is the feeling that they are "bad parents for not giving their child a good time eating all the food he or she wanted" (60).
- Doing nothing, and going on as before, is willing “their child to be happy”. It is protecting the child against anxiety and daily stress, and avoiding the

risk of reducing personal satisfaction. It is, finally, accepting their child as he/she is (8,46,57,59).

First and foremost, parents adopted protective attitudes. They compensated for their child's lack of self-esteem and bad social image with their love and sought to make the home a sanctuary (74). Parents wanted their child to be happy — to have a good self-image, and no peer-related problems.

Here obesity actually justified a strong, protective, infantilising bond between parents and child. It appears as the "cement" in the parent-child bond (46,56,58,60).

Thus adopting a therapeutic attitude necessarily requires parents to completely reappraise the use they make of food, and above all their own relationship with food. Parental "modelling" can be used as self-directed therapy, whereby the parents compel themselves to eat a balanced diet, to engage in sporting activities to assist their child in his or her efforts. Some parents may even consider that the problem concerns the whole family, and that the whole family's eating habits should change (16,52,54,55,73,75).

Healthcare professionals

One element that appears often in the discourse of the professionals is the feeling that the different modes of care are ineffective and that their discourse has no influence with the families: the barriers to managing weight and feeding behavior are too numerous, especially at home. Durable change is difficult to achieve: alliances form between family members, and families sabotage care. Some professionals thus tend to suggest that there is “no effective treatment” (69). When treatment does succeed, they tend to think that they played no role in it (62).

The main barrier to successful treatment appears here to be the parents, because of their difficulty in recognising obesity, their probable role in its origins, the use of food in affective relationships, and their difficulty in restraining the child (8,63–66,69).

Subjective evaluation of treatment

Parents and children have assessed the many different treatment methods they have been offered: the quality of meetings, inpatient programs, the role of dietary advice, sports, the importance of working on self-esteem, and parental involvement. Perceptions of efficacy and satisfaction vary too widely to find a consensus about treatment methods.

According to the parents interviewed, the medical attitude they respond to best is one that is empathetic, direct and clear. Discourse that aims to inculcate feelings of responsibility in parents or children are frequently not well received. (16,56,75,77). Some studies have sought to acquire an understanding of subjective experiences of care in inpatient settings. These different inpatient programs are seen as effective in the short term, but their long-term results are perceived as too variable and difficult to predict (58,68,78,79). Cognitive-behavioural therapy was also evaluated by some parents, who considered it was effective, especially for self-esteem, self-confidence, and parental involvement (61,80). The merits of diet-based care was a matter of dispute by the participants interviewed: the impact is small when it is implemented on its own among adolescents, who do not have a positive perception of it (11,42).

Overall, physical activity was the intervention praised most highly by young people and by healthcare workers. It is synonymous with good health, it bolsters the self-image image, which is in turn important for overall functioning and for self-esteem, as long as the activity is recreational rather than competitive (51,70,71). Nevertheless, sports can sometimes reinforce children's negative self-image when it generates a vicious circle where the specific skills and abilities needed are a source of discouragement. The solution would be to look into non-formal exercises and varied activity over time (14,51,68). Dealing with self-esteem is seen as a major factor by adolescents and parents. This can be achieved by mediation, in particular, in the field of sport, or in settings that facilitate discussion and exchange (8,41,51,70,80).

A last major aspect is the importance of the whole family being involved in the treatment — the nuclear family and the extended family. The "parenting"

dimension and the need to consider the family as a whole are seen as central issues (48,58,62,66,69).

Discussion

This meta-synthesis of qualitative research on childhood and adolescent obesity has generated three categories of data in relation to children and adolescents, parents, and health-care professionals.

Their subjective accounts were organized according to three axes of experience, each describing important aspects of obesity care: diagnosis and awareness of the problem (seeing others, seeing oneself); the attempt to understand its cause and making sense of it (understanding others, understanding oneself); representations and assessment of treatments (treating others, treating oneself). One interpretation links all three types of experience: it is the place and the importance of words in the doctor-child-parent relationship.

In recent years, the medical model of care has shifted from a disease-centered to a patient-centered model. This transformation is based on the need to enhance patients' participation in their treatment, improve shared decision-making, and create common goals (81–83). A prerequisite of this model is the creation of a common representation of the condition. Failure to do this may compromise the success of the treatment (patient refuses, or does not follow it, treatment is ineffective) (84). In the context of child and adolescent illness, this means unifying the perspectives of children, parents and health-care professionals, who participate equally in the care process (85–88).

However, in the matter of child and adolescent obesity this appears to be no small challenge (19,89–91). Our results show not only the existence of different representations of obesity for the three categories of participants, but also the difficulty of sharing these representations to move beyond the individual perspective and achieve a common representation.

For children and adolescents this difficulty is related to the lack of early awareness of obesity as a problem; as we saw earlier, this arises only at a late stage and in relation to how others see them. Of the feelings that children and adolescents described, few concern any health-related issues. Instead,

appearance and social considerations were of primary importance, both for awareness of obesity and motivation for treatment. This reveals a different impetus for change, compared with the parents' and professionals' goals for the child, as well as different treatment needs.

For parents the challenge is mainly linked to questions raised about their own food-related behaviour. Another important issue that prevents them from talking to the child about obesity is their reluctance to upset them. We can go even further to suggest that the role of food in family relationships is almost certainly related to the problem. This clearly contributes to a lack of shared representations (92).

Finally, among health care professionals this reticence is related to the topic itself, which is considered to be sensitive and often even taboo. Talking about obesity with parents means going beyond medical concerns, and facing the problem of family relationships. Talking to the child involves confronting social prejudices and stigma. In both cases, the risk that physicians want to avoid is the loss of therapeutic partnership by dealing with issues they do not quite consider as medical. Thus it seems that health care professionals refrain from action and from broaching the problem in a multidimensional manner, and this in turn might explain their pessimistic attitudes toward treatment.

The history of scientific consideration of obesity, and in particular of its definition, shows the ambiguities, disagreements and discussions among specialists about how to define, understand, and treat it (12,93,94). Our findings show that these same doubts seem to occur within the doctor-parent-obese child triangle. Yet carers and families need the support of clear, consensual shared knowledge to construct the relationship and the treatment (88). The heterogeneity of the concept of obesity destabilises the therapeutic relationship and its construction.

Conclusion and recommendations for future research and practice

One important issue in the doctor-child-parent relationship in this context is the need to exchange their representations of obesity. This must come before any plan of care, at the early meetings, sharing an understanding of what the child or

adolescent is experiencing. If representations are not shared, the relationship and all the stages of treatment are likely to come to nothing.

The difficulty of putting obesity into words finds an echo in the difficulty researchers have in recommending consensual attitudes to the carers and families. Health-care professionals working with these patients need to be aware that they must actively facilitate discussion about the representations.

Health workers must also expand their understanding of obesity by incorporating the representations of obese children and their parents in order to match treatment plans to their needs and expectations. Qualitative studies, which work closely with the participants, are invaluable aids in bringing these representations to light. Development of this kind of research thus appears essential in the treatment of obesity.

Limitations

The main limitation of this work is methodological. Meta-syntheses are based on the analysis of qualitative studies, themselves based on data collected from participants. Some authors see this as a third level of construction – the first level is the construction of the participants themselves, i.e. the results; the second level is the interpretation and understanding of the authors, i.e. the discussions and conclusions (95). However in our analysis we did not have access to the initial data, but only to partial data, and the authors' interpretations. Thus any generalisation should be cautious. Nevertheless, the wide scope for triangulation – numerous participants, numerous viewpoints, varied teams, numerous different methods – suggest a reasonable scope for generalisation.

Despite the care taken in the search for relevant articles, it is possible that some were missed. The choice of selecting only English written articles may have limited the taking into account of the cultural variability, and thus limited the generalisation of the results. Nor did we take into account the socioeconomic context and the age of the participants included in the different studies, although this may influence perception of and behaviour towards food. The articles selected nonetheless come from many different countries, and participants had various socio-cultural backgrounds, and were different ages. Again, these factors suggest that the results can be carefully generalised.

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Tables and Figures

Table 1 – Search terms

Boolean		AND OR	AND OR	AND OR
Search term	Obes*	Young* Child* Teen* Adolescent Parent Mothers Fathers Caregiv* Family Health Personnel Professionals Health professionals Paediatricians Practitioners Physicians Nurses Primary Health Care	Perception Attitude Feeling Awar* Knowledge Belief View Perspective Opinion Observ* Experience Image Self concept Barriers Treatment Psychology Etiology Management	Qualitative method Qualitative study Qualitative research Thematic analysis Content analysis Constant comparative method Grounded theory Narrative Focus group Interview Semi-structured In depth
Sub-Total	1	17	18	12
Total	48 words			

* truncation symbol used to search database for word ending variants

Table 2 – Databases searched

Database	Date	Results
Pubmed	1990 to 2011	1391
Scopus	1990 to 2011	3304
Embase	1990 to 2011	893
PsycInfo	1990 to 2011	439
CINAHL Plus	1990 to 2011	426
		Total 6453

Table 3 – Main characteristics of the studies

Author	Year	Aim	Country	Population			Type of interview	Method
				Type	Age	Nb		
Alm & Al (70)	2008	To examine the reasons for managing weight, to investigate the barriers and facilitators to achieving behavior goals, and to assess how a behavior coach affects the goal-setting process of obese inner-city adolescents in a weight management program.	USA	C	M 15	18	SSI	Bouije
Amiri & Al (40)	2011	To Investigate adolescents' perception regarding overweight/obesity and explore barriers to a healthy life style among Iranian adolescents.	Iran	C	15-17	51	7 FG 15 SSI	Grounded Theory
Barlow & Al (61)	2007	To examine paediatricians' experiences discussing obesity and its treatment with patients and families to determine practice behaviours and perceived effect.	USA	H	-	8	SSI	Deductive focused coding techniques (Patton)
Bolling & Al (74)	2009	To seek feedback from parents of overweight preschoolers on terms for overweight and treatment strategies pediatricians could use to help parents improve diet and activity for their children.	USA	P	2-6	23	FG	Morgan & Krueger
Bruss & Al (71)	2005	To provide a better understanding of the relationship between child feeding practices and childhood obesity, focusing on family messages related to child feeding, and to guide the design of effective interventions.	USA	P	6-10	32	ETH + FG	Coordinated management of meaning theory (Bogden & Biklen)
Chamberlin & Al (65)	2002	To examine WIC health care professionals' perceptions about the challenges that exist in preventing and managing childhood obesity, in order to develop new approaches that address the different perceptions about obesity held by clients and health care professionals	USA	H	-	19	3 FG 6 SSI	Thematic
Chen & Al (41)	2005	To explore the themes of the experience of overweight female students during the weight reduction period after their participation in health promotion counseling programs	Taiwan	C	19-22	30	7 FG	Thematic
Curtis (42)	2008	To explore the experiences of young people with obesity within the secondary school environment in relation to areas of concern prioritized by the HSP (Healthy School Programme)	UK	C	10-17	18	FG 1 SSI	Cross sectional (Mason)
Daley & Al (69)	2008	To explore the experiences of participants of the Sheffield Obesity Trial, an exercise therapy intervention	UK	C	M 13	23	SSI	Dey
Dapi & Al (8)	2007	To investigate factors influencing rural and urban adolescents' food perceptions during a time of nutritional transition in Cameroon, Africa.	Cameroon	C	12-15	15	SSI	Grounded Theory
Davis & Al (58)	2008	To learn more about rural parents attitudes concerning pediatric obesity, the barriers they face in trying to help their children attain a healthy weight status, and the pediatric weight loss services currently available in their rural communities	USA	P	8-10	21	8 FG	Thematic
Davis & Al (43)	2008	To attempt to understand the experience of childhood obesity from the perspective of African American children who were experiencing a BMI at the 95th and higher percentile.	USA	C,P	8-11	17 C 17 P	FG	Giorgi, Krueger
Dixey & Al (57)	2006	To find out from parents what they thought about the WATCH IT programme, and in a more general sense to find out more about the role of parents in weight management	UK	P	8-16	24	FG	Framework analysis technique (FAT)
De La Luz & Al (39)	2010	To explore obese adolescents' perceptions about obesity among students in the seventh to ninth grade of a public school in Mexico.	Mexico	C	11-15	24	SSI	Thematic (Minayo)
Edmunds (76)	2005	To explore parents' perceptions of help-seeking experiences with health professionals.	UK	P	4-15	40	SSI	Grounded Theory
Edmunds (55)	2008	To elucidate some of the social impacts that overweight and obesity in children has on families	UK	P	1-15	48	2 FG SSI	Grounded Theory
Edvardsson & Al (66)	2009	To describe maternal and child health nurses' experiences of communicating and raising issues with parents about children's overweight.	Sweden	H	0-6	10	SSI	Graneheim & Lundman
Goff & Al (67)	2006	To explore the following topics related to obesity training in pediatric residencies: current training offered, perceived barriers to training, recommendations for improving training, and educators' attitudes and beliefs regarding the role of the pediatrician in obesity prevention and management.	USA	H	-	16	SSI	Thematic
Griffiths & Al (44)	2008	To examine the relationship between obesity and victimization, and the impact this has on peer relationships.	UK	C	12-17	5	SSI	IPA (Smith)
Grønbæk (45)	2008	To analyse families' narratives, recorded in clinical interviews, concerning the family's insight regarding their child's overweight, the development of obesity, and motivational factors for taking action in relation to the family's socio-demographic conditions	Denmark	F	10-12	53	SSI	Analytic-strategic mix narrative method (Olsen)
Haugstvedt & Al (59)	2011	To deepen the knowledge of how parents of children who are overweight or obese experience their parenthood.	Norway	P	4-11	17	FG	Grounded Theory
Hester & Al (77)	2010	To uncover detailed qualitative accounts of experiences of implementing healthy lifestyle changes following an	UK	C	14-16	5	SSI	Self-Determination Theory

		intensive stay at residential weight-loss camp						(Ryan)
Hughes & Al (56)	2010	To understand mothers' perceptions of their overweight children's weight, when the children were enrolled in Kentucky's Special Supplemental Nutrition Program for Women, Infants, and Children	USA	P	3-5	21	SSI	Thematic
Jackson & Al (53)	2005	To develop understandings into the views of a group of mothers with an overweight or obese child, about their child's overweight or obesity.	Australia	P	1-15	11	FG	Feminist approach (Cook)
Jackson & Al (73)	2005	To explore the strategies a group of mothers of overweight and obese children were using and planned to use in the future to assist their children to achieve a healthy weight.	Australia	P	1-15	11	SSI	Feminist insights (Cook)
Jackson & Al (72)	2007	To develop understandings into women's experiences of mothering an overweight or obese child.	Australia	P	1-15	11	FG	Feminist insights
Jain & Al (54)	2001	To explore mothers' perceptions about how they determine when a child is overweight, why children become overweight, and what barriers exist to preventing or managing childhood obesity.	USA	P	2-5	18	3 FG	Thematic
Kaufman & Al (47)	2007	To generate a deeper understanding of the childhood obesity epidemic among groups most deeply affected in New York City (Latinos), to inform the New York City Department of Health and Mental Hygiene's neighborhood-targeted obesity prevention programs	USA	F	1-21	60	ETH	Ethnographic
King & Al (62)	2007	To investigate the perceptions of GPs about overweight and obesity in children and adolescents, including the extent to which they perceive it as a concern, the factors they see as causal, what actions they consider might be needed, and their sense of responsibility and self-efficacy.	Australia	H	-	26	FG	Thematic
Lindelof & Al (13)	2010	To explore obese adolescents' and their parents' views on the formers' obesity, especially to gain knowledge about barriers and motivational factors that influence obese adolescents' ability to lose weight	Denmark	C,P	14-16	15 C 22 P	ETH	Narrativity (Bourdieu, Ricoeur)
Mériaux & Al (48)	2010	To describe everyday experiences of life, body and well-being in children with overweight.	Sweden	C	10-12	16	FI	Content Analysis
Murtagh & Al (10)	2006	To identify the physical and psychological levers and barriers to weight loss experienced by obese children using qualitative techniques	UK	C	7-15	20	3 FG SSI	FAT
Neumarks-Ztainer (49)	1999	To gather in-depth descriptions of the experiences of overweight adolescent girls to understand how they view themselves and their social context, and to compare body and self-image issues among African-American and Caucasian overweight girls	USA	C	14-20	50	SSI	Content analysis
Owen & Al (78)	2009	To explore children's and parents' views and experiences of attending a hospital-based childhood obesity clinic, in order to inform the development of services in primary care	UK	C,P	7-18	11 C 21 P	SSI	Thematic
Pagnini & Al (7)	2009	To investigate similarities and differences in the perceptions of parents, adolescents, General Practitioners and education professionals regarding childhood overweight and obesity.	Australia	C,P,H	-	58 C 87 P 43 H	26 FG 17 SSI	Thematic
Redsell & Al (63)	2011	To explore obesity-related knowledge of UK HCPs and the beliefs and current practice of general practitioners and practice nurses in relation to identifying infants at risk of developing childhood obesity.	UK	S	-	18	SSI	Phenomenologic (Fade, Boyatzis)
Shrewsbur & Al (15)	2010	To canvass the nature of adolescent-parent interactions about weight, particularly overweight, and to explore ideas of how to foster supportive discussions regarding weight, both in the home and with family doctors.	Australia	C,P	13-16	21 C 32 P	9 FG	Thematic
Stewart & Al (60)	2008	To provide insight into the perceptions of parents of obese children as they ''journey'' from pre-treatment to end of treatment.	UK	P	-	17	SSI	FAT
Stewart & Al (79)	2008	To explore the thoughts and feelings of parents whose children had undertaken dietetic consultations either employing behavioural change techniques or delivered by dieticians with no formal training in these techniques	UK	P	5-11	17	SSI	FAT
Sussner & Al (52)	2008	To study the influence of immigrant status and acculturation on the development of overweight in Latino families	USA	P	-	51	6 FG 20 SSI	Content analysis
Thomas & Al (50)	2009	To explore overweight/obese youths' perceptions of the meaning of 'healthy body weight', barriers and facilitators to healthy body weight attainment and what would effectively enhance and support their healthy body weight behaviours	Canada	C	14-16	11	SSI	Inductive content analysis
Turner & Al (68)	2009	To explore practitioners' views of primary care as a setting in which to treat childhood obesity.	UK	H	-	30	SSI	FAT
Walker & Al (64)	2007	To explore GPs' and practice nurses' views in relation to their role in treating childhood obesity.	UK	H	-	18	SSI	FAT
Wills & Al (38)	2006	To discover whether, and how, weight and body size infiltrate other areas of teenagers' everyday lives; how these issues are experienced and perceived; and whether medical definitions of fatness are reflected in young peoples' discursive concerns.	UK	C	13-14	36	SSI	Thematic
Wong & Al (51)	2010	To examine how cultural influences play a role in family eating habits that contribute to the problem of childhood obesity in Chinese society in Hong Kong.	China	F	7-13	32	SSI	Grounded theory

C: Children; P: Parents; H: Health Professionals; F: Family; M: mean age; SSI: semi-structured interview; FI: Free Interview; FG: focus group; ETH: ethnographic procedure; GP: General Practitioner

Table 4 – Quality assessment criteria (from Pocock et al 2010 (23))

		Quality assessment for each study			
Criteria	Examples	Met criterion	Partially met	Did not meet	Unclear
Scope, Purpose	Explicitly stated aims/objectives of research	41	4	0	0
	Adequate description of research context				
Design	Appropriate use of qualitative methods	38	7	0	0
Sample	Adequate description of sample used, sample identification and recruitment.	29	15	1	0
	Appropriate sample size for study objectives.				
	Selection criteria explicit.				
	Inclusions/exclusions explained.				
Data collection	Adequate description of data collection methods	44	1	0	0
Analysis	Adequate description of methods used to analyse data	36	7	2	0
Validity, Reliability	Clarity regarding how evidence and conclusions derived.	38	6	1	0
	Evidence of assessment of validity				
Generalizability, Transferability	Clarity about extent to which evidence can be generalized beyond settings and study participants.	38	7	0	0
Credibility, integrity, plausibility	Evidence is credible and gives meaningful illumination of lives/contexts being researched.	39	6	0	0
Ethics approval	Evidence of ethical approval by an appropriate body	35	10	0	0

Table 5 – Results from study quality evaluation

	Alm & Al (70)	**Amiri & Al** (40)	**Barlow & Al** (61)	**Bolling & Al** (74)	**Bruss & Al** (71)	**Chamberlin & Al** (65)	**Chen & Al** (41)	**Curtis** (42)	**Dalev & Al** (69)	**Dani & Al** (8)	**Davis & Al** (58)	**Davis& Al** (43)	**Dixev & Al** (57)	**De la Luz & Al** (39)	**Edmunds** (76)	**Edmunds** (55)	**Edvardsson & Al** (66)	**Goff & Al** (67)	**Griffiths & Al** (44)	**Grønbæk** (45)	**Haugstvedt & Al** (59)	**Hester & Al** (77)	**Hughes & Al** (56)	**Iackson & Al** (53)	**Iackson & Al** (73)	**Iackson & Al** (72)	**Iain & Al** (54)	**Kaufman & Al** (47)	**King & Al** (62)	**Lindelof & Al** (13)	**Mériaux & Al** (48)	**Murtagh & Al** (10)	**Neumarks-Ztainer** (49)	**Owen & Al** (78)	**Paemini & Al** (7)	**Redsell & Al** (63)	**Shrewsburv & Al** (15)	**Stewart & Al** (60)	**Stewart & Al** (79)	**Sussner & Al** (52)	**Thomas & Al** (50)	**Turner & Al** (68)	**Walker & Al** (64)	**Wills & Al** (38)	**Wong & Al** (51)
Objectives, theme	T	T	T	P	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	P	T	T	T	T	T	T	T	T	P	T	T	T	T	T	T	P	T	T	T	T	T	T	T
Design	T	T	P	T	T	T	P	P	T	T	T	T	T	T	T	T	T	T	T	P	T	T	T	P	P	T	T	T	T	T	P	T	T	T	T	T	T	T	T	T	T	T	T	T
Sample	T	T	P	T	P	T	P	P	T	T	T	P	P	N	T	P	T	T	T	P	P	T	T	P	P	P	T	T	T	T	T	P	T	T	T	P	T	T	T	T	T	T	P	T
Data collection	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	P	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T
Analysis	T	T	T	T	T	T	P	P	T	T	T	T	T	P	T	T	T	T	T	T	T	T	T	P	N	N	T	T	P	T	T	T	T	T	T	T	T	T	P	P	T	T	T	T
Validity, reliability	T	T	T	T	T	T	T	P	T	T	T	T	T	P	T	T	T	T	T	P	T	T	T	P	N	P	T	T	P	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T
Scope for generalisation	T	P	P	T	T	T	T	P	T	T	T	T	P	T	T	T	T	T	T	T	T	T	T	P	P	T	T	P	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T
Credibility, integrity, plausibility	T	P	T	T	T	T	T	T	T	T	T	T	P	P	T	T	T	T	T	T	T	T	T	P	P	P	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T
Ethics committee	T	T	N	T	T	T	N	T	T	N	T	T	T	T	T	N	T	T	T	N	T	T	T	T	T	T	T	N	T	T	T	T	N	T	T	T	T	T	T	N	T	T	N	N

N: not met; P: partially met; T: totally me

Table 6 - Principal themes

	Seeing and seeing oneself	Understanding and understanding oneself	Treating and treating oneself : Overall apprehension of the care itinerary
Children and adolescents	Physical appearance and body are criteria for obesity: "*Referred to someone having floppy skin; having too much skin over their ribcage; having fat hanging down or having flabby arms.*" (38) Obesity as a symbol of power, wealth and good health: "*Food helps them 'to be in shape,' which means 'to be valiant, not to be heavy and tired.*" (8) Awareness arises from the scrutiny of others: "*At school I'm a different person to who I am at home*" (10) Obese adolescents are subject to taunting and bullying: "*Three years I tried not going to school because I used to get bullied and my mum got took to court.*" (42) **N=17** (7,8,10,15,38–45,47–51)	Involvement of outside factors: "*My body type is how God meant it to be, you can't change that*" (40) Implication of a strong hereditary factor: "*It's normal that I'm fat, my family is fat.*" (39) Lack of family support as a factor in sustaining the condition: "*To explain their unhealthy eating habits they (a) accused their parents for buying and serving unhealthy food..*" (13) Fear as a factor in maintaining the condition: "*I hate gym class. I hate wearing shorts. I feel so embarrassed about how I look in shorts.*" (70) **N=13** (7,13,15,38–40,45,47,48,50,51,69,70)	The desire to lose weight is gender-related: "*The girls were more interested in their appearance and nice clothes than the boys were.*" (45) The main source of support is the family: "*All participants reported that family support was a factor for a healthy body weight, and they referred mostly to the support from mothers*" (50) Dealing with issues of self-esteem is central: "*All participants raised the issue of self-esteem, which concerned their perceptions of others' judgments.*" (50) Dietary strategies are ill-suited to their expectations : "*Dieticians never listen*" (10) Social and family barriers to sporting activities : "*For the girls in the study, the lack of safe places and conditions for exercise was a barrier to increasing physical activity.*" (70) **N=15** (10,13,15,38–42,44,45,48–51,70)
Parents	Parents underestimate their child's weight: *"Children had entrenched weight problems before their mothers became concerned"* (53) Parents evaluate obesity via behaviour, activity and appearance of their child: *"Well, if he gets lazy and wants to lay around and doesn't want to be active then a flag [about weight] will come up"* (56) Parents have prejudice about obese children that they do not apply to their own child: *"Whereas she plays every sport, she does things, she's not a couch potato, you know."* (58) Parents find it difficult to talk about obesity with their child: *"If I say something, all hell breaks loose"* (7) Parents have difficulty talking about obesity with their doctor: *"This is an important message for GPs not to avoid the issue of excess weight but to raise it in a sensitive manner and offer parents help."* (60) **N=15** (7,15,45,47,51–60,73)	Parents construct their representations from social and cultural messages: "*Everybody tells me you've got to eat rice, no limit*" (71) Parents construct their representations from medical messages: "*Some kids are (always going to be overweight) that's the way they're going to be no matter what they do, it's in their genetics.*" (58) Parents construct their representations from family messages: "*I think that if a person is born into a family that's always frying stuff or always eating really fatty foods, not food that's good for you, that they will learn those habits that their parents or grandparents or whoever they live with are doing.*" (56) Obesity as secondary to lack of regulation of eating behaviours: "*We try to say, 'Slow down your eating, you have to let your tummy realise that it's full so it tells your head'…*" (73) **N=16** (7,13,45,47,51–54,56–59,71–74)	Ambivalence – taking action and controlling, or doing nothing: "*Our main finding was that the parents felt ambivalent in their parenthood of their overweight child between taking preventive actions with respect to the child's weight and, at the same time, which could be in conflict, also taking care of the child's self-esteem.*" (59) Adopting a hyper-protective attitude: "*It was important to them that children still experienced their homes as a sanctuary from the problems of the outside world, and felt loved, accepted and valued within the home.*" (73) Parental modelling: "*I've recently joined a gym and I'm trying to lose weight myself, for myself and also to show the girls that it doesn't matter how old you are or how big you are, you can do more. You don't have to sit in front of the television all the time.*" (72) Feelings of frustration: "*Participants expressed uncertainty, frustration and anxiety about knowing how to help their child. They were aware of the complex nature of obesity and the emotional fragility of their children, particularly where weight was concerned.*" (72) **N=14** (7,15,45,51,53–59,72–74)

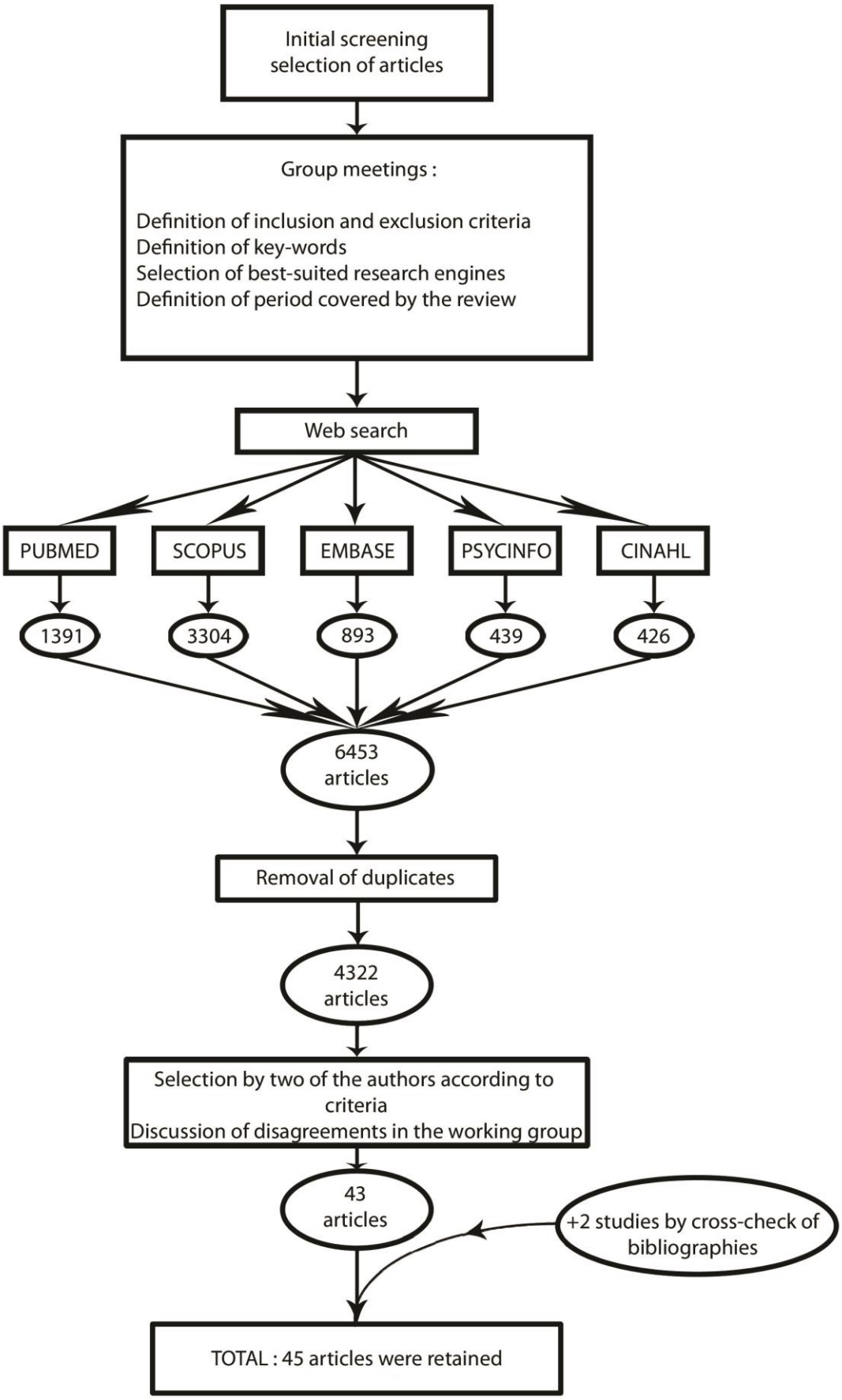
Health-care professionals	Therapists use BMI, appearance and eating behaviours for diagnosis: "*You see a trend where you're going up and… they're playing video games all day, and… they're eating soda and chips. So I might be more inclined in that child, even if they are on the 75th percentile, to bring something up*" (61) GPs adopt the role of informers, and treat comorbidities: "*I don't think we are managers of obesity, but really just to manage in terms of co-morbidity or high risk factors*." (64) They have great difficulty broaching obesity with families : "*I would invariably not talk about it, unless patients come in and talk to me about it*." (7) They are afraid of damaging family functioning if they talk about obesity : "*It is very hard to tell a mother to stop feeding their child so much… it's deeply psychological thing… Yes, it's sort of 'love and food'*." (62) **N=9** (7,61–68)	Social, educational and emotional impoverishment involved in obesity: "*I think yeah I think poor social circumstances as well and diet because I think from what I've seen I think the children poor, but when I mean poor in social circumstances I'm not talking about money, I'm talking about a family unit*." (63) Lack of family cohesion involved in obesity : "*I think in the great majority of cases we are talking about social issues really […] Families are getting more disruptive. There's a general lack of cohesion within families*." (68) **N=9** (7,15,61–66,68)	General feeling of powerlessness : "*I just feel kind of powerless . . . what more can I do?"* (61) "*Perhaps we don't feel capable of coping with childhood obesity, we don't know what to do really*" (64) The family as a barrier to change : "*We spend time with a family discussing diet and exercise... but they are not generally enthusiastic about diet and exercise regimes*" (64) **N=7** (7,61–65,68)

Subjective evaluation of treatment

Empathetic discourse: "*Some health professionals were empathetic and helpful, with one paediatric dietitian described as 'brilliant'*" (76)
Short-term efficacy of inpatient treatment: "*Despite experiencing an intensive and successful program, including weight control success in the home environment, the difficulties of sustaining both healthy behaviors and weight management persist.*" (77)
Cognitive-behavioural therapy effective on self-esteem: ''*I think it was good for her self-esteem, she was really starting to feel good about herself. Which is more important, she has really taken it on*'' (60)
Debatable impact of dietary methods: "*Negative experiences of dieting and of dietitians were identified as a barrier to action. Most participants attributed unsuccessful weight-loss regimens to unrealistically strict dietary guidelines*." (10)
Popularity of physical activity: "*It gets you out of the house and not eating, and also exercise helps you and it can help you lose weight*." (69)
Physical activity should be informal : "*…non-formal exercise such as cycling, walking, social activities involving fun and playfulness should be encouraged*." (13)
The importance of dealing with issues of self-esteem : "*Program planners must be mindful that youths need support and guidance toward media buffering, self-acceptance, and other tools to improve self-esteem*." (50)
The importance of involving the family in care : "*As the child's obesity affects the whole family, it seems logical to include the whole family in its management*." (57)
N=23 (7,10,13,15,38,40,41,47,50,55,57,60,61,65,67–70,74,76–79)

N = frequency of theme over all 45 studies

Figure 1 – Flowchart for selecting studies



Article 2 - Une métasynthèse sur les perceptions des jeunes, de leurs parents et de leurs soignants sur les comportements suicidaires

Le deuxième article est également une métasynthèse qui s'intéresse aux comportements suicidaires des adolescents. Il a été publié en anglais en mai 2015 dans la revue internationale *Plos One* (revue indexée dans Medline, impact factor à 3,54).

Ce deuxième article est le fruit d'une double réflexion :

- sur la thématique des comportements suicidaires. Il s'agit également d'une thématique que nous connaissons bien sur le plan clinique. Nous avons également exploré cette question avec une perspective phénoménologique en amont (Orri et al., 2014).
- sur la méthode de métasynthèse. Notre premier travail de métasynthèse nous a permis de mettre en évidence certaines limites de notre travail. L'angle de perspective choisi (moteurs de recherche médicaux) limite les résultats, et notamment ne permet pas d'inclure suffisamment la perspective socio-anthropologique pourtant essentielle à la compréhension de ces questions complexes de soin. Ceci est en partie modulé par l'utilisation, dans la discussion des résultats, de données supplémentaires issues de la littérature (parus sous forme de livres et de manuscrits notamment). Une deuxième limite est la question de l'analyse de la qualité qui doit être d'avantage pensée (exclusion ou pas des articles, utilisation d'outils validés…). Le guide d'évaluation utilisé (Quality Framework) est en effet peu utilisé en dehors des questions d'obésité. Nous avons ainsi poursuivi notre travail de réflexion méthodologique en nous appuyant sur les plus récentes publications dans le domaine. Nous avons affiné notre démarche en particulier autour de l'inclusion et de l'analyse de la qualité.

Cette métasynthèse est donc plus aboutie sur le plan méthodologique. La sélection des études s'est faite sur les bases de données précédentes, en y

ajoutant la base *Social Sciences Citation Index* (SSCI). Cela a permis d'élargir notre sélection à des articles issus du champ des sciences sociales. La méthode d'analyse qualitative s'est affinée et affirmée. Enfin, nous avons choisi d'utiliser pour cette deuxième étude le Critical Appraisal Skills Programme (CASP, 2013) afin d'évaluer la qualité des études. Nous avons complété cet outil en proposant une pondération des critères en 3 grades (totalement rempli, partiellement rempli, non rempli).

Notre choix d'étudier la question du suicide de l'adolescent se justifie par un raisonnement assez proche de celui de l'obésité. Il s'agit d'une question majeure de santé publique en France et dans le monde (le suicide est la deuxième cause de mortalité des 15-25ans), et les difficultés de prise en charge persistent malgré une évolution constante des moyens depuis les années 1980. Ainsi, ¼ des hospitalisations d'adolescents pour tentative de suicide en France sont des récidives suicidaires. Le suicide est par ailleurs une question sociale, culturelle, philosophique, et anthropologique, et cette complexité est particulièrement bien appréhendée par la recherche qualitative.

Notre démarche a consisté en une revue systématique de la littérature concernant le suicide des adolescents et des jeunes adultes. Les bases de données interrogées étaient Pubmed, Scopus, Embase, PsycInfo, CINAHL, et SSCI. Les articles interrogeant les jeunes suicidants, leurs parents ainsi que les soignants qui les prennent en charge étaient inclus.

L'expérience suicidaire est décrite à l'aide de trois axes. Sur le plan individuel, l'expérience de dépressivité, de difficultés de contrôle de soi et le sentiment d'impuissance rapportés par les jeunes sont partagés par l'entourage et les soignants. Sur le plan de l'expérience relationnelle, les jeunes comme leur entourage rapportent un sentiment de différence, de rejet, de manque d'écoute et d'incompréhension. Les changements dans le tissu relationnel sont à la fois précipitants et protecteurs des récidives. Enfin, l'expérience sociale et culturelle regroupe les difficultés à s'intégrer au groupe social, ainsi que les barrières et facilitateurs sociaux et culturels aux soins. Au centre de l'expérience suicidaire partagée, c'est le sentiment d'incompréhension qui s'inscrit dans les discours de tous les participants. Cette incompréhension semble sous-tendue par les réelles

difficultés d'empathie pour ces jeunes. En effet, le passage à l'acte suicidaire est un acte violent dirigé contre soi mais aussi contre l'autre, qui gèle toute capacité de partage de l'expérience de souffrance. Une réflexion est nécessaire, qui pourrait inclure des propositions issues des théories de l'intersubjectivité, afin de permettre une restauration des capacités d'empathie de soignants et de l'entourage et d'améliorer la prise en charge de ces jeunes.

Metasynthesis of Youth Suicidal Behaviours: Perspectives of Youth, Parents, and Health Care Professionals

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Title: Metasynthesis of Youth Suicidal Behaviours: Perspectives of Youth, Parents, and Health Care Professionals

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Abstract

Background: Youth suicide is a major public health issue throughout the world. Numerous theoretical models have been proposed to improve our understanding of suicidal behaviours, but medical science has struggled to integrate all the complex aspects of this question. The aim of this review is to synthesise the views of suicidal adolescents and young adults, their parents, and their healthcare professionals on the topics of suicidal behaviour and management of those who have attempted suicide, in order to propose new pathways of care, closer to the issues and expectations of each group. Methods and Findings: This systematic review of qualitative studies — Medline, PsycInfo, Embase, CINAHL, and SSCI from 1990 to 2014 — concerning suicide attempts by young people used thematic synthesis to develop categories inductively from the themes identified in the studies. The synthesis included 44 studies from 16 countries: 31 interviewed the youth, 7 their parents, and 6 the healthcare professionals. The results are organised around three superordinate themes: the individual experience, that is, the individual burden and suffering related to suicide attempts in all three groups; the relational experience, which describes the importance of relationships with others at all stages of the process of suicidal behaviour; and the social and cultural experience, or how the group and society accept or reject young people in distress and their families and how that affects the suicidal process and its management. Conclusion: The violence of the message of a suicidal act and the fears associated with death lead to

incomprehension and interfere with the capacity for empathy of both family members and professionals. The issue in treatment is to be able to witness this violence so that the patient feels understood and heard, and thus to limit recurrences. Keywords: qualitative research, meta-synthesis, suicide, adolescent, young adult, perception

Introduction

Suicide and attempted suicide are a major public health issue in Europe and throughout the world [1]. Youth – that is, adolescents and young adults, aged 15 to 29 years, and also referred to here as young people – are particularly at risk of suicidal behaviours: suicide is the second leading cause of death among this age group [1], and the rate of suicide attempts is estimated to be 10 to 20 times higher than that of completed suicides [2,3]. Worldwide, there are officially around 164 000 deaths by suicide annually among those younger than 25 years [4] and the sex ratio ranges from about 2 to 6 young men for every young woman. Distribution at the international level is heterogeneous, with prevalence higher in Eastern Europe, lower in Central and South America, and intermediate in the USA, Western Europe, and Asia. The rates in Africa are generally unknown [5–7].

In numerous Western countries, the incidence of suicidal behaviours among young people increased considerably from the beginning of the 20th century into the 1990s [7,8], when large-scale campaigns of prevention and the introduction of antidepressant treatments resulted in a significant reduction in deaths from suicide [9–12]. Although these prevention campaigns are ongoing [13], recent trends in many countries show that the prevalence rates of suicidal attempts have stopped falling; they are either becoming stable or starting to rise again [5,14,15].

Numerous theoretical models have been proposed to improve our understanding of suicide [3,5,10,16–19], but medical science has struggled to integrate all the complex aspects of this question at the interface of medical, sociological, anthropological, cultural, psychological, and philosophical issues [20]. Explanatory models are necessary, to allow us to think about suicide in a new and different way. Meta-synthesis is a useful and recognised tool that can

help to understand complex medical questions [21–24]. It appears to be a tool of choice for apprehending questions about suicide and allows in-depth access to the perspectives of the different groups involved with young people who have attempted suicide.

We conducted a systematic review of the qualitative studies about suicidal behaviours in the medical literature and a meta-synthesis (through a thematic analysis) of 44 studies that interviewed youthful suicide attempters, their parents, and the healthcare professionals providing care to them [25,26]. We decided to include these three groups of participants because they are the main protagonists of the therapeutic relationship in this context. Our objective in conducting this review was to describe the experience of attempted suicide and its management as closely as possible from the perspective of each of these three groups, covering the issues and expectations of each, so that we can propose new pathways for thinking about and improving care.

Methods

Design

We used thematic synthesis [27]. Our procedure took place in four stages: designing the research, that is, defining the question, subjects, types of studies to include, and the protocol; the search for and selection of articles; and the analysis itself, in two separate stages, first a descriptive portion in which we determined and compared themes, and then an interpretive stage in which we constructed a descriptive schema of the phenomenon, original proposals that we then examined from the perspectives of theory, the literature, clinical practice, and care [25,27]. These steps increase both the possibilities for generalisation and the strength of these generalisations.[28] Our method is consistent with the ENTREQ statements [29]. (S1 Table)

Here are the six steps of our method:

1. Definition of the research question (summarised in the aims and objectives);
2. Identification and selection of studies;
3. Quality assessment of the selected studies;

4. Analysis of the papers, identification of themes, and translation of the themes across studies;
5. Generating analytical themes and structuring the synthesis
6. Writing the synthesis.

Selection of studies

We conducted a systematic search for qualitative studies specifically devoted to suicidal behaviours in young people (step 2). The QUALIGRAMH working group (Qualitative Group for Research in Adolescent Mental Health, INSERM U 669, Maison des Adolescents, Hôpital Cochin, Paris), composed of specialists in qualitative research and disorders of young people, defined the study criteria.

The papers were selected only if they met the following criteria:

- Used solely qualitative methodology.
- Specifically concerned suicidal behaviours in adolescents and young adults (referred to hereafter as youth or young people).
- Interviewed:
    - Young people who were suicidal, or who had attempted suicide in their youth, or
    - Parents of these youth, or
    - Medical professionals who provide care to suicidal youth.
- Were published in English or French between 1990 and May, 2014 (the period covering most of the qualitative articles about suicide).

Finally the following studies were excluded:

- Studies using quantitative or mixed methodologies;
- Studies in the general population exploring prevention of suicide or social representations of suicide in adolescents and young adults;
- Studies concerning solely deliberate self-harm or non-suicidal self-injury.

The study was conducted from January to May 2014. An initial search identified a selection of papers, from which we collected keywords. Based on this selection

as well as on existing literature reviews about suicide [30–32], the research group drew up a list of keywords, a mix of free-text terms and thesaurus terms related to suicidal behaviours, youth, and qualitative research [33,34] and compiled a list of databases indexing qualitative studies in the fields of medicine, sociology, and psychology [25,35]. We performed our search on July 1, 2013 (and updated it on May 31, 2014) (Table 1 and S2 Table).

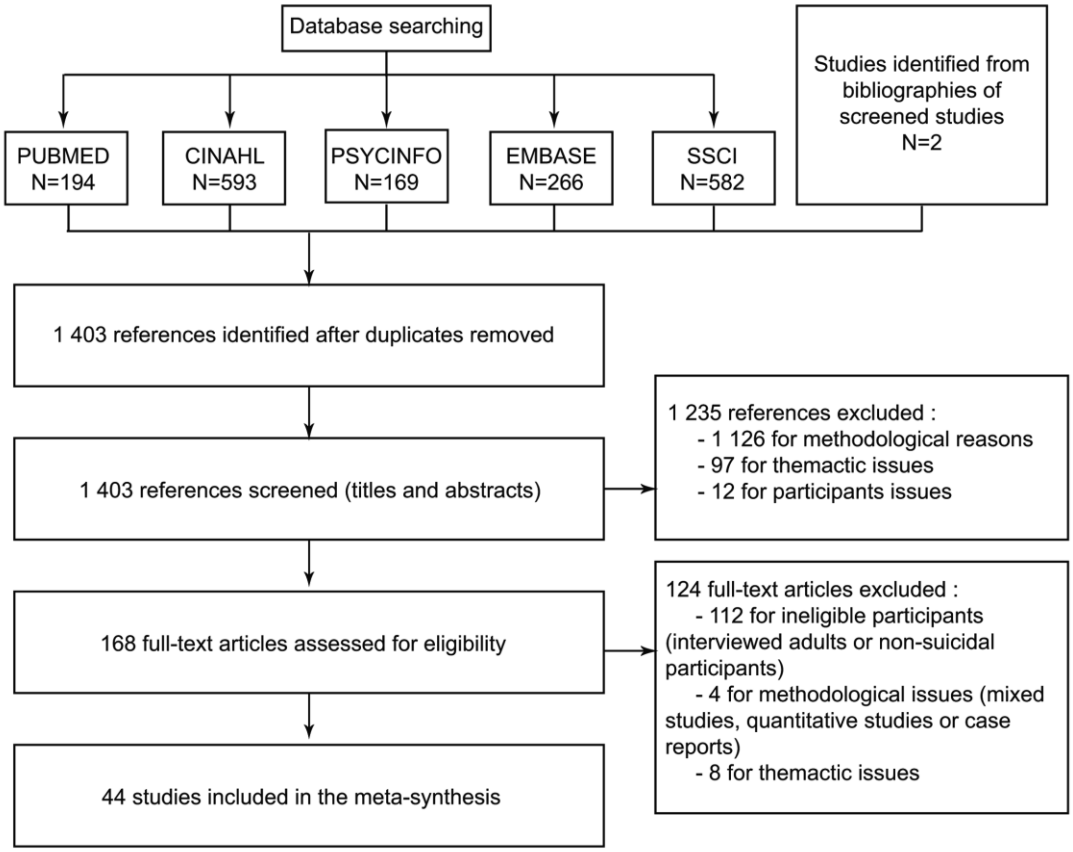
Table 1 – Web searches – January 1, 1990 to July 1, 2013 (updated on May 31, 2014)

Databases	Free-text terms keywords	Thesaurus terms keywords	References
MEDLINE	26	19	194
CINAHL	26	27	593
PsycInfo	26	30	169
Embase	26	21	266
SSCI	26	0	582
TOTAL	**-**	**-**	**1804**

In all, we obtained 1804 references, 1403 of which remained after removal of duplicates (Fig. 1). Two authors (JL and MO) screened all titles and abstracts, according to the relevance of their theme and methodology. If the abstract was not sufficient, the full text was read. Disagreements were resolved during working group meetings. For example, we initially included all studies concerning deliberate self-harm or non-suicidal self-injury in our selection. After discussions and literature review [3], we decided to exclude all these papers because we do not think that the issues of suicide and self-harm are identical: the question of death is posed differently for these two groups of subjects. Another issue was whether or not to include mixed studies, given that the best way of dealing with mixed methods remains unclear [25]. After consulting these papers, we concluded that they did not contribute to our thematic framework and decided to exclude them from the analysis. Full texts of potentially relevant papers were then examined, and a second selection was performed (the papers excluded at this point and the reasons for their exclusion are listed in S1 File). After removal of studies that did not meet the criteria defined above, 42 papers

remained. Scanning the reference lists for more potentially relevant papers provided 2 more papers. In all, the review finally included 44 studies, around 2.5% of the papers screened. This rate is consistent with the findings of other such meta-syntheses [25,33,34].

Fig. 1. Flowchart for selecting studies



Assessment of paper quality

The evaluation of quality (step 3) is necessary to enable discussion of the studies and to ascertain the value and integrity of the data used. The working group chose a tool widely used for medical meta-syntheses, the Critical Appraisal Skills Programme (CASP) [32,36]. Two researchers (JL and MO) independently performed the evaluation, and the working group reached a consensus about it. Table 2 summarises the quality evaluation criteria.

Table 2 – Evaluation of the quality of the studies according to the Critical Appraisal Skill Programme (CASP)

Criteria	Totally Met[1]	Partially Met[1]	Not Met[1]
1. Was there a clear statement of the aims of the research?	41	3	0
2. Is a qualitative methodology appropriate?	41	3	0
3. Was the research design appropriate to address the aims of the research?	39	5	0
4. Was the recruitment strategy appropriate to the aims of the research?	31	10	3
5. Were the data collected in a way that addressed the research issue?	37	6	1
6. Has the relationship between researcher and participants been adequately considered?	25	10	9
7. Have ethical issues been taken into consideration?	36	1	7
8. Was the data analysis sufficiently rigorous?	24	16	4
9. Is there a clear statement of findings?	28	9	7
10. How valuable is the research?	29	15	0

[1] Number of studies

Data analysis

We followed the procedure described by Thomas and Harden (2008) to analyse the data [27]. The analysis (step 4) included a careful reading of the titles, abstracts, and complete papers as well as repeated rereadings. One researcher (JL) extracted the formal characteristics of the studies, while he and two others (ARL and MO) independently extracted and analysed the data, which were then compared during meetings. We used thematic analysis to develop categories inductively from the first-order themes identified in these studies. Afterwards, the translation work involved comparing themes across papers to match themes from one paper with those from another and ensure that each key theme captured similar themes from different papers. Finally, we ordered these translation results into a framework containing three superordinate themes (step 5). This step is more interpretive, since the group decided to organize the themes through a more conceptual line of argument. The last step consisted in expressing the synthesis in a useful form (step 6). This process led not to a summary of the different studies included, but to an interpretation of the papers, described in the discussion. Research meetings were held regularly to discuss the results obtained. The triangulation of sources – meta-synthesis does this by definition – and the triangulation of reviewers made possible a high level of rigour in the results [37,38].

Results: description of the studies

Presentation of the included studies

In all, we examined 31 studies that questioned young suicide attempters, by semi-structured interviews, free interviews, focus groups, internet forums or chat rooms, or questionnaires. Six studies questioned healthcare professionals who provide care to suicidal youth; these used semi-structured interviews and focus groups to collect date from doctors, nurses, psychiatrists, psychology students, social workers, and counsellors. Finally, seven studies questioned the parents of suicidal youth, in structured, semi-structured, or unstructured interviews. Studies come from 16 different countries: 16 from North and Central America (Canada, Nicaragua, and the USA), 13 from Europe (Italy, Norway, Sweden, and the United Kingdom), 3 from Africa (Ghana and South Africa), 6 from Asia (Hong Kong, Israel, Iran, Vietnam and the Republic of Korea), and 6 from Oceania (Australia and New Zealand). Tables 3, 4 and 5 detail the characteristics of each study.

Table 3 – Main characteristics of the studies (Studies interviewing young people who have attempted suicide)

Study	Aims	Country	Nb[1]	Age[1]	Data coll.[2]	Analysis method
[81]	To identify different contexts in which young people harm themselves and propose a theory generated from the data that might link family circumstances, suicidal cognition, suicidal phantasies and the nature of the self-harming act itself.	UK	23	9-16	SSI, Q	Grounded theory
[62]	To explore the accounts of young adults who engage in self-harming and suicidal behaviours and use websites dedicated to these issues, in order to develop a broader understanding of these websites and to identify potential implications for future research.	UK	10	18-30	SSI	Foucauldian discourse analysis
[63]	To develop an understanding of non-fatal suicidal behaviour (NFSB) from the perspective of individuals of a relatively homogenous group of respondents who shared characteristics which placed them at a particularly high risk for NFSB (i.e., female adolescents of Indian origin)	South Africa	10	14-17	SSI	Thematic analysis
[43]	To explore young people's transitions towards resistance against future suicidal behaviours.	New Zealand	27	15-24	SSI	Discourse analysis
[44]	To highlight the complexities evident in young people's engagement with discourses of depression and mental ill-health, which constitute a dominant part of the construction of their suicidal behaviour, and examine the ways in which they negotiate and renegotiate relationships with dominant constructions of mental ill-health that combine youth, suicidal behaviour, deviance, and psychopathology.	New Zealand	30	16-25	SSI	Discourse analysis
[64]	To develop a grounded theory of recovery from the perspective of young adults with a history of repeated suicide-related behaviour who completed at least one cycle of a specific treatment intervention: psychosocial/psychoeducational intervention for people with recurrent suicide attempts (PISA).	Canada	16	18-25	SSI	Grounded theory
[45]	To examine how adolescents who have overcome suicidal thoughts and behaviours perceive the role of attachment relationships in the process of becoming suicidal.	Canada	50	13-26	SSI	Grounded theory
[46]	To explore how adolescents perceive attachment relationships as helping them overcome suicidality.	Canada	50	21,9	SSI	Grounded theory
[65]	To capture adolescents' own perspectives regarding the factors implicated in their psychological distress, to better understand how these youth conceive the causes of their depression/suicidal ideation, and to focus on the quality of the relationships between suicidal adolescents and their parents and the role these relationships	Israel	10	15-19	SSI	Consensual qualitative research

	played in the adolescents' psychological distress or resilience.					
[50]	To identify common themes in answer to the question, "What was the experience of young adults who felt suicidal, made the decision, and attempted to end their lives?"	Canada	5	24-27	SSI	Phenomenology
[48]	To illustrate the role 3 major factors played in one teenager's experience of becoming and overcoming being suicidal: mental processes, cognitive development, identity formation, and autonomy-seeking.	Canada	1	20	SSI	Grounded theory
[49]	To develop an understanding of how adolescents and emerging adults experience and respond to emotions from the subjective perspective of previously suicidal participants.	Canada	50	15-27	SSI	Grounded theory
[47]	To develop an understanding of how adolescents overcome suicidality from the subjective perspective of previously suicidal female participants, using a resilience framework to conceptualize the process.	Canada	13	17-26	SSI	Grounded theory
[51]	To gain further insight into the factors that may buffer L/B/G youth from suicidality and present a model integrating the known risk factors, with the resiliency factors that emerge.	New Zealand	8	18-25	SSI	Grounded theory
[83]	To explore the experiences of adolescents seeking help online for suicidality, focusing on online helper therapy as a key finding.	Canada	10	Ado	M	Content analysis
[52]	To explore perceived causes, and discover triggers and processes leading to suicidal behaviour among adolescent girls in Leo´n, Nicaragua, and to develop a tentative conceptual model to understand the pathways to suicidal behaviour.	Nicaragua	8	15-19	SSI	Grounded theory and Content analysis
[53]	To explore the thoughts of students who had experienced suicidal ideation but had not attempted suicide, and to identify specific themes of suicidal ideation among college students in South Korea.	Republic of Korea	134	18-28	Q	Qualitative content analysis
[66]	To learn first-hand from young men about the context of their suicidal behaviour and to use this contextual perspective as a basis for thinking about service delivery and clinical care.	UK	36	<30	SSI	Grounded theory
[54]	To illuminate the sociocultural contexts of attempting suicide among Iranian youth.	Iran	25	14-17	FI	Thematic analysis
[55]	To identify the factors that contribute to suicide, to review the signs and characteristics associated with these factors, to interview Mexican-American students in special education programs for emotional and behavioural disorders who exhibited various characteristics of suicidal thoughts and/or have attempted suicide, to explore effective prevention programs, and to provide suggestions for school personnel.	USA	8	13-18	SSI	Phenomenology
[67]	To explore and understand the pathways leading to attempted suicide among young men in Nicaragua, and to investigate the interplay between structural conditions and individual coping strategies, as well as to achieve an in-depth understanding of what triggers suicidal behaviour in young men.	Nicaragua	12	15-24	SSI	Grounded theory
[56]	To explore the perspective of adolescents who have directly engaged in suicidal acts (in either single or repeated suicide attempts).	Italy	16	17-25	SSI	IPA
[68]	To investigate what individuals who were suicidal between the ages of 13 to 18 report as being helpful in psychotherapy to overcome suicidal thoughts, feelings and behaviours, in order to increase our understanding of helpful aspects of psychotherapy in previously suicidal adolescents.	Canada	37	21,8	SSI	Multidimensional scaling and clustering analysis methods
[69]	To analyse the interactions between the users of a non-professionally run deliberate self-harm message board, focusing on the function of the message board as manifested in users' interactions.	UK	174	Adolescents	M	IPA
[57]	To explore the possible reasons for the participants' suicide attempt, focusing on demographic characteristics, psychosocial factors, and environmental and cultural factors.	South Africa	14	13-20	SSI	Thematic analysis
[70]	To examine how patients who had previously presented to hospital after an episode of deliberate self-poisoning, but who had not harmed themselves in the past two years, discussed their self-harming behaviour and the health services they received at the time, and to identify how patients accounted for this resolution.	UK	9	16-25	SSI	Grounded theory and narrative analysis
[58]	To explore in depth how adolescents with suicidal ideation perceived their family, school, and peer relationships, including as support systems, and to shed light on the operation of school guidance, together with parental and peer support in maintaining adolescent psychological health and in preventing suicide.	Hong-Kong	13	11-18	SSI	Data display, data interpretation, and drawing conclusions
[59]	To explore further the qualitative responses of hospitalized, suicidal adolescents after the AFI intervention in order to determine whether participating in the AFI intervention was meaningful to the participants.	USA	11	13-18	SSI	Phenomenology
[60]	To explore the suicidal process, suicidal communication and psychosocial situation of young suicide attempters in a rural community in Hanoï	Vietnam	19	15-24	SSI	Thematic analysis
[84]	To highlight the sociocultural themes that affect suicide attempts by Korean adolescents, contributing to a cross-cultural perspective that informs scholars in other nations of multiple realities, cultural awareness, and complex cultural interrelationships.	Republic of Korea	1	16	LH	Life history
[61]	To examine the conditions in which suicide attempts occur among young Latinas, how they experience the circumstances that led to the attempt, and what they say precipitated their suicide attempts and what triggered the act.	USA	27	11-19	SSI	Grounded theory

[1]Number and Age of participants; [2] Data collection; FI: free interviews; LH: life history; M: message boards; Q: questionnaires;

SSI: semi-structured interviews; UK: United Kingdom; IPA: Interpretative phenomenological analysis

Table 4 – Main characteristics of the studies (Studies interviewing parents)

Study	Aims	Country	Nb[1]	Age[1]	Data coll.[2]	Analysis method
[71]	To describe the experience of mothers living with suicidal adolescents.	Canada	6	-	FI	Phenomenology
[72]	To interview surviving family members who had lost a teenager by suicide to increase the understanding of the circumstances in which these families live.	Sweden	10	-	FI	Grounded theory
[74]	To provide a qualitative understanding of the experiences of preparedness for the suicide death of a young adult son or daughter from the perspective of parents	Australia	22	-	SSI	Narrative analysis
[73]	To explore parents' experiences following the suicide death of their young adult child.	Australia	22	-	SSI	Narrative analysis
[75]	To explore the kind of experiences that suicidees had when seeking support from healthcare services in the period leading up to their death, as perceived by close family and friends.	Australia	15	-	SSI	Grounded theory
[77]	To understand suicide from the perspective of those who knew the deceased and were caught up in events surrounding the death.	UK	14	-	SSI	Narrative analysis
[76]	To build a tentative conceptual model, grounded in the parents' views, of the process behind suicide in boys.	Sweden	51	-	SI	Grounded theory

[1]Number and Age of participants; [2] Data collection; FI: free interviews; SSI: semi-structured interviews; SI: structured interview; UK: United Kingdom

Table 5 – Main characteristics of the studies (Studies interviewing health professionals)

Study	Aims	Country	Nb[1]	Age[1]	Data coll.[2]	Analysis method
[42]	To explore the attitudes towards young people who engage in suicidal behaviour, among nurses, nursing lecturers, and doctors.	UK	8		SSI	Constant comparative method
[78]	To focus on suicidal behaviour in young people by exploring the perceptions of this phenomenon among nurses and doctors working in accident and emergency, paediatric medicine and child and adolescent mental health services.	UK	45	-	SSI	Grounded theory
[82]	To explore nurses' and doctors' perceptions of young people who engage in suicidal behaviour, using a social semiotic theory to build an interpretation of the meanings nurses and doctors assign in relation to this group of young people	UK	45	-	SSI	Grounded theory and Social semiotic
[85]	To examine the attitudes of psychology students toward suicidal behaviour to understand the meaning(s) they assign to the act, and to discuss the consequences for suicide prevention in Ghana.	Ghana	15	-	SSI	IPA
[80]	To explore how outpatient counsellors engage parents following a youth suicide assessment and to add to the literature of engaging parents in rural environments, specifically around the issue of gun safety and suicide prevention.	USA	24	-	FG	Inductive analysis
[79]	To develop knowledge about the significance of ASIST (Applied Suicide Intervention Skills Training) for Public Health Nurses' (PHNs) practice.	Norway	16	-	FG	Qualitative content analysis

[1]Number and Age of participants; [2] Data collection; FG: focus groups; SSI: semi-structured interviews; UK: United Kingdom; IPA: Interpretative phenomenological analysis

Quality assessment

Our evaluation found that on the whole the quality of the studies was good (Table 2 and S3 Table). The ethical considerations were sometimes insufficient, and the description of the analytical method sometimes inadequately detailed. This flaw was most often explained by editorial constraints (maximum word lengths that were more appropriate for the presentation of quantitative than qualitative research).

No study was excluded from the analysis on the basis of this evaluation. The original authors of the meta-ethnographic approach report that poorer quality studies tend to contribute less to the synthesis [25,39–41]. Further, there is no consensus on the role of quality criteria and how they should be applied, in particular for systematic reviews (see also [25,38]).

Results: Thematic synthesis

The thematic analysis clearly showed three superordinate themes of experience. The first is individual experience, comprising three subthemes: *the experience of distress, self-control, and the parents' impotence in the face of the suicide attempter's distress*. The second superordinate theme is the relationship with others, including the subthemes: *changes in the relational distance*, *feelings of difference and rejection,* and *the experience of incomprehension*. The third main theme concerns the social and cultural aspects of the suicidal act. The themes that compose it are: *failure to fit in the group,* and *sociocultural facilitators and barriers to suicide and its management* (Tables 6, 7, 8 and 9).

Table 6 – Themes identified in each study

Study	Experience of distress	Self-control	Parental importence in the face of the young suicide attempters' distress	Changes in the relational distance	Feelings of difference and rejection	The experience of incomprehension	Failure to fit into the group	Sociocultural facilitators and barriers to suicide and its management
[42]	Y			Y	Y	Y		Y
[78]			Y	Y	Y	Y		Y
[82]				Y		Y		Y
[81]				Y				
[62]		Y				Y		Y
[63]		Y		Y			Y	Y
[43]	Y			Y		Y	Y	
[44]	Y	Y					Y	
[64]		Y						
[45]	Y	Y		Y	Y		Y	
[46]	Y	Y		Y		Y		
[71]			Y	Y	Y	Y		Y
[65]		Y		Y	Y	Y	Y	Y
[50]	Y	Y		Y	Y	Y	Y	
[48]	Y	Y		Y			Y	
[49]	Y	Y		Y	Y	Y	Y	Y
[47]	Y	Y		Y		Y		
[51]		Y		Y	Y	Y	Y	Y
[83]				Y		Y		Y
[52]				Y	Y	Y	Y	Y
[53]	Y	Y		Y	Y	Y	Y	Y
[66]		Y		Y		Y	Y	Y
[54]	Y			Y	Y		Y	Y
[72]			Y	Y		Y	Y	Y
[74]			Y		Y	Y		
[73]			Y					Y
[55]	Y			Y	Y	Y	Y	
[67]		Y		Y	Y		Y	Y
[75]			Y					
[85]						Y		Y
[56]	Y	Y		Y	Y	Y	Y	
[77]			Y		Y	Y	Y	Y
[68]		Y		Y		Y		
[69]		Y		Y		Y		Y
[57]	Y			Y	Y	Y	Y	
[70]		Y		Y	Y	Y	Y	
[80]			Y	Y		Y		Y
[58]	Y			Y	Y	Y	Y	
[79]			Y	Y		Y		Y
[76]			Y	Y	Y	Y	Y	
[59]	Y	Y			Y	Y	Y	
[60]	Y			Y	Y	Y	Y	Y
[84]				Y	Y		Y	
[61]	Y	Y		Y	Y		Y	Y
TOTAL	18	21	10	35	24	32	26	24

Table 7 – Quotations from participants and authors of primary studies to illustrate each theme of superordinate theme 1 (Individual experience)

Themes	Quotations from participants in primary studies	Interpretations of findings offered by authors
The experience of distress	Depressive symptoms: You're going to school, you're getting an education, but you're depressed. [50] Failure, defeat, self-disgust: I hated myself. [49] Getting better: I was really surprised at my will to live, to sort of keep going. [43]	Depressive symptoms: There is consistency in recognising the components we identify as despair. [49] Failure, defeat, self-disgust: She had a strong feeling of hatred toward herself; she saw herself as being fat, ugly, stupid, and blamed herself for difficulties in her life and in her family. [48] Getting better: Many participants emphasised 'thinking positively' about their lives and concerns as a useful component of problem solving.[43]
Self-control	Impression of losing control: I felt I had no control over my life. Whatever I did didn't matter. It was going to happen anyways. [49] Regaining control: I became quite social after coming out. I spose, yeah . . . I always just needed to constantly find that affirmation, it wasn't just something that I could say okay I've had enough, you know. I constantly needed that every day. ... and it was also about my whole, my self-esteem and confidence just totally went up every time as well, and if I stopped or something they'd just go down again. [51]	Impression of losing control: Thinking about suicide became a means of coping. [49] Regaining control: Leon's strategy similarly involved problem-focussed coping; he actively strengthened his social support network to secure self-esteem. [51]
Helplessness of the parents in the face of the suicide attempters' distress	The experience of parents: There was nothing in place for my other children. They were stuck in the middle; so was the whole family. You can't give them [the other children] what they deserve because you are too wrapped up. [71] The therapists' experience of helplessness: I think it is more a feeling inside which you see and just mull over and then not worry about it but at the time it's like well I have done this and that is all I can do. I can't do any more. It is also on their part—you get frustrated. Because they just don't take your help when you're offering it—and you think well, "listen to me I am trying to help you I am trying to give you these opportunities but you don't want them". [78]	The experience of parents: They experienced a loss of hope for an ending to the self-destructive behaviours, for a return of their formerly happy lives, for a bright and prosperous future for their children and themselves. [71] The therapists' experience of helplessness: Part of the feeling here is that whatever you [nurses and doctors] do, nothing seems to work. However, the core meaning is about suicidal behaviour being treated in a specialist setting which is used to 'changing things' with physical interventions. The meaning of frustration in this sense was linked to not being able to treat suicidal behaviour as if it were a physical illness. [78]

Table 8 – Quotations from participants and authors of primary studies to illustrate each theme of superordinate theme 2 (Relational experience)

Themes	Quotations from participants in primary studies	Interpretations of findings offered by authors
Changes in the relational distance	Relational difficulties: My parents didn't care. They didn't want to help me or make things better. They just wanted to rag on me... that's how everything seemed. And if nobody cared, why bother trying to live? In my mind I was alone. There was nobody. [45] Suicide as a form of communication: It's a powerful form of communication and the trick is what they are trying to communicate to us. [82] Rapprochement with family: My parents started treating me older and me and my dad would go out and have a coffee and then we'd be able to sit and talk and then slowly we got like this relationship. I'd go out more so then I wasn't always home with my mom and so we got along better too. [48] Need for attention: When I use the term `attention seeking' I don't use it in a derogatory way… I would suspect that there are a group of people who deliberately self-harm who will do it for... attention seeking primarily. [42]	Relational difficulties: The unavailability of care and support created distant interpersonal relationships, feelings of loneliness and withdrawal. They became vulnerable to suicidal behaviours and, as they described, were unable to turn to others for comfort. [45] Suicide as a form of communication: While it can be seen that suicidal behaviour is a communicative event, the meaning in the message was not always clear. [82] Rapprochement with family: Changes in significant attachment relationships accompanied Marie's shift to resolving her suicidal state. [48] Need for attention: The doctors in the study also showed they felt suicidal behaviour could be a way of `seeking attention', but that it occurred in specific groups. [42]
Feelings of difference and rejection	The adolescents had a feeling of difference and rejection: Nobody saw the likes of me when I came to this school. Everybody was tripped out because my pants had holes all the way down, and my hair was long, and everybody was just kind of like surprised to see someone like me. They [students] even gave me nicknames like warlock. They just gave me a whole bunch of them—let me see warlock, psycho, Freddie, Jason You know like the horror movie people? It was like that. When someone would dare me to do something, I'd do it. [55] Parents feel rejected: Yeah, yeah, because he was just splitting the whole family, wasn't he? He didn't have any regard for anybody's property. He would come and go as he pleased. [. . .] And we said to him, 'Well, you don't want to be part of this family. It's obvious you don't, because you wouldn't be doing the things you're doing'. So he went to live with his friend for a while. [77]	The adolescents had a feeling of difference and rejection: Social desirability may be important in the prediction of suicidal ideation and interest. [55] Parents feel rejected: The parents are clearly wrestling with the unspoken question: 'Why, despite all we did for him, did he do this to us?' They leave their audience in no doubt that he abused them, their love, their trust and their property. [77]
The experience of incompre-hension	Young people do not feel understood: They do not understand my situation and their scolding is unreasonable. I think they need to love me as they gave birth to me. It seems bad to scold me for no reason. They do not understand me actually. [58] Parents do not understand their children: We felt so abandoned and let down, didn't we, because I don't think as parents we deserved – we hadn't done anything to deserve that really. [77] Feeling understood plays a role in getting better: Online allows me to have an outlet, an understanding and to share all the weird uncomfortable bits and not be judged – if someone does judge me, I'm fine with it because I don't feel threatened by online people, they are not in my life, I don't have to see them every day and to be honest a lot of them can offer a lot of help because they have had similar experiences. [62]	Young people do not feel understood: They were dissatisfied with their unharmonious family relationships, and criticised their parents for not understanding them, trusting them or listening to them. It made them feel that they were not being valued in their family. [58] Parents do not understand their children: The suicide makes sense to them when set in the context of a long history of aimlessness and anomie, but the question of why, despite their love and care, he was unable to carve out a meaningful path through life remains largely unresolved. [77] Feeling understood plays a role in getting better: This discourse of empathetic understanding provides website users with two positive and socially valued identities: the understander and the understood. [62]

Table 9 – Quotations from participants and authors of primary studies to illustrate each theme of superordinate theme 3 (The social and cultural experience)

Themes	Quotations from participants in primary studies	Interpretations of findings offered by authors
Failure to fit into the group	The young people do not succeed in meeting social norms: Having a high marriage portion for girls is considered to be socially prestigious: When my family and I went to their house to propose marriage and, during the procedure of wedlock, my father fell in discussion and then quarrelled with my beloved's uncle on the marriage portion. Finally we had to leave their home. I became so Narahati [sad] for a few months. Last week, again we went to their house. This time they started quarrelling and did not agree to our marriage. [54] Parents feel and transmit the emotions associated with this failure: He was having some sort of twitches in his body and was forced to act up in school, to get up and run off, or some such thing, so that no one would see these strange tics, and this was very shameful for him. In the sixth grade, he said ''if I don't get some help for this, I'm going to kill myself. [76]	The young people do not succeed in meeting social norms: In addition to interpersonal reasons, social stigma regarding outside marriage relationships appeared as one of the main causes of troubles in love. Both girls were trying to keep their relationship with their boyfriends secret because of strong family opposition. The shame of exposing the relationship was so unbearable for one of the girls that it led her to attempt suicide. [54] Parents feel and transmit the emotions associated with this failure: The parents could tell the boy was ashamed of being too short, twitching his head, arms and legs, or sweating too much […] His suicide note could say that he hated his body. [76]
Sociocultural facilitators and barriers to suicide and its management	Religious beliefs protect against suicide: God gave me this life. I cannot take it until he wants to. [52] Religious beliefs can promote suicide: We had good times at the beginning but now all of them became Christians; my mother, my grandma and my nanny so, no matter what I say, all is a sin! If I mention a word, I'll be punished with hell; the devil will take me far away, and so forth. [52] The media promote an idealised image of suicide: They have done it to themselves, but they have done it in an very naive state of mind not knowing much and I think they have done it from—well you see things like this on TV a great deal, in soap operas and stuff and that's what they watch. [82] Stigmatisation limits parents' access to care: Parents whose children's death certificate says carbon monoxide poisoning or hanging, it is very confronting I suppose, especially if there are younger children involved. Whereas if your child died of cancer it is more acceptable in society's view – your child dies and otherwise they would still be here. [73] The right to die: I do think people have a right over their lives because things are not so clearly defined - there are a lot of grey areas in life and I think there is a difference between committing suicide because they feel there is no hope and not prolonging it because of something else - perhaps some medical reason - they don't want life to be lengthy . . . [42] The taboo of suicide: For the majority of people it is a bad act. For a very few people it is an understandable act – for some of those it's an acceptable act. But for the majority – bad. [42] The social group protects and supports: I find it to be a very supportive community, and have made several good friends there, and everyone there has something in common, that they find life in general difficulty to do, people there have a work package of empathy and can give great advice and support.. [62]	Religious beliefs protect against suicide: Leo n (Nicaragua) society traditionally has strict religious norms and values. This is reflected in the view on suicide. [52] Religious beliefs can promote suicide: Some of the informants hinted at the weakening of religious norms and values. Religion sometimes causes conflicts in relationships with parents and relatives. [52] The media promote an idealised image of suicide: In a similar way, one view might be that the media today contribute to creating a moral panic around suicidal behaviour in young people by reconstructing it as deviant behavior. [82] Stigmatisation limits parents' access to care: The stigma long associated with death, and more specifically to suicide, has affected these parents, leaving them feeling unsure and unable to discuss their child's death openly. [71] The right to die: Both nurses and doctors appeared to share this view relating to the right young people have over their lives, and this coincided with the degree of choice that should be handed over to the individual. [42] The taboo of suicide: They seemed to hold an underlying perception that suicide was wrong and that their child should not have done this. [74] The social group protects and supports: A community member is someone who belongs to a group, is socially integrated, and socially valid. This represents another positive identity for people who use self-harm and suicide websites. Outsiders may lack important knowledge shared by the community and may be unhelpful or even threatening. [62]

Individual experience

The three themes belonging to this superordinate theme describe the individual burden and suffering that suicide brings about, albeit in different forms, in all three groups.

The experience of distress

The experiences of sadness and of mental or emotional distress are at the heart of the accounts provided by both the youth and the professionals [42–61].

Most of the participants describing their suicidal experience mentioned feelings of depression: sadness [45,50,54,60], sorrow [54], mental pain [49,53,54,56], despair [49,50,54,56,60], detachment [45,56], anger, and irritability [45,49,50,54,60]. The professionals may diagnose depression [44,47,50, 55,57,61], but certainly not on a routine basis [42].

The experience of failure is at the heart of this distress [43,44,46–54,56,58,59]: decreased self-esteem [46,49,56], feelings of uselessness [50,52–54,58], incompetence [49], and worthlessness [50,53,54]. Participants sometimes even mentioned self-hatred [48].

Improvement corresponds to exit from the downward spiral of failure [43,46,47, 51,59]. The youth interviewed reported the reappearance of positive thoughts [43,47] and restoration of their self-esteem [46,51,59].

Self-control

The second subtheme concerns self-control: simultaneously, loss of self-control, impossibility of coping, leading to despair and suicidal action, but also to an attempt to regain control by expressing distress [44–51,53,56,59,61–70].

Many suicidal youth have the impression that they have lost control of their existence [45,49,50,56,63,70], that they can no longer take part in decisions that concern them, no longer influence the course of their own lives [45]. Dealing with their problems, doubts, and fears [44,48,50,61,64,67] or with their painful experiences or strong emotions [44,48,61,68] seems impossible to them. They no longer understand themselves [44,45,56]. Life becomes both hopeless and senseless [50]. Suicide might then appear as a means of regaining self-control [49,56,64].

By talking about themselves, by understanding themselves, changing their point of view, giving a meaning to their existence, these young suicide attempters regain control over their lives [44,46–48,51,53,59,61,62,64–66,68,69]. The therapeutic space [44,46,48,59,64,65,68,69], but also the spaces for individual [51,53] and community [62] expression are settings that enable the young to cope [47,61], where they can rediscover themselves, learn to understand themselves and one another [46,47,61,64,68], change their perspective about things [46,64], give a new meaning to their existence [47,48,61,66], and imagine a positive future [47].

Parents' impotence in the face of the suicide attempters' distress

The family and the treatment teams both reported similar experiences of the distress of these youth, dominated by feelings of helplessness, guilt, anger, and the impression that they are losing control of these young people [71–80].

The family experiences their child's first suicide attempt in a way resembling the youth's experience: loss of hope, blame, guilt, self-recrimination, a sense of total failure; rejection, isolation, and incomprehension; powerlessness and helplessness, loss of control [71–76]. The realisation is often sudden, which destabilises the parents still further [71,74]. Whether they were drowning in guilt [71,74,75] or rejecting the responsibility for their child's suffering [77], parents confided their difficulties in rallying round. Their impression of the healthcare system as useless, futile, or rejecting [75,76] reinforces their experience of helplessness.

Healthcare professionals too can feel impotent in the face of the young people's individual feelings of distress: they have the impression that the interventions that they can suggest are not appropriate [78]; those who provide care for these youth wish they had specialised interventions and specific training available [78,79]. They are also helpless in dealing with the parents, whom it might be difficult to help to respond usefully when their attitudes show resistance or shock or when they minimise the risk [80].

Relational experience

The three subthemes here describe the importance of the relationship with others at all stages of the suicidal process: i) during the phase when suicidal ideation develops, ii) during the events precipitating the act itself, iii) during the phase of crisis resolution.

Changes in the relational distance

At each stage of the suicidal process and its care, the youths, their parents, and the healthcare professionals described movements of rapprochement and of distancing from one another [42,43,45–58,60,61,63,65–72,76,78–84].

The stability of the relationship is important for the youth, as it is for their parents [45,48–50,52–55,57,58,60,61,63,65,67,71,72,76,84]. All of them reported that relational difficulties, separations, mourning, and feelings of insecurity are elements that engender suicidal ideation [45,48,50,52–55,57,58,60,61,63,65,67,84]. Breaches and break-ups, conflicts, separations, losses, and absence can all explain the decision to act [50,52–57,61,63,65,67,72,76,84]. Communication is difficult, and suicide attempts can serve to express one's distress to the others [45,48–50,52,55–58,60,61,72,76], or to take vengeance on one or more family members or friends [56]. Many professionals also consider that attempted suicide is a mode of communication [42,79,80,82]: according to them, youth use suicide as a powerful form of communication, a way to say something important [82]. The challenge is thus to help the family hear this complex message so that they can work together effectively with the young person [80].

After the suicide attempt, the parents move closer to their child, who becomes a constant preoccupation and sometimes requires constant monitoring.[71,72,76] For the youth, the rapprochement with their families, the reconnection, the improvement of relationships and communication are simultaneously conditions for and consequences of getting better [43,46,47,49,52,56,58,61,66,67,70,81,84]. Relationships with the healthcare provider are central to treatment: the professional must be an unconditional source of love and support [46,51,68,69,83]. Professionals noted that the need for attention is at the heart of treatment: attention from family and friends, but also and especially from

healthcare providers, who must commit themselves strongly to the relationship and give of themselves. This type of commitment embarrasses some, who underline the need for particular skills, but also the risk of wasting time, for the result is never certain [42,78–80].

Feelings of difference and rejection

Feelings of difference and rejection are present throughout the suicidal process: rejection by peers, family, friends, but also sometimes professionals [45,49–61,65,67,70,71,74,76,77,84].

The feeling of being different from others is very present in the young people's discourse, shared by the parents [45,49–61,65,67,70,71,76,77,84]. The youth find themselves singular, cannot succeed in resembling their peers, feel isolated and rejected [49,51,54–56,58,59,67,84]. The rejection is based most often on elements of reality: harassment at school, bullying, or discrimination based on sexual orientation [45,50,51,58,61,65]. The youth also say that they find it hard to fit into their family, which is often broken, or in conflict [50,52,55,57,60]. The fear of being judged by others — because of their differences and their inability to adopt the group's common values — amplifies the feeling of solitude and the real isolation [49,52,53,55,57,70]. In some contexts, boys are more vulnerable to isolation than girls [67]. Many parents, reporting what their child has confided in them, confirm these feelings of difference and rejection [71,76,77]. The parents also sometimes feel rejected by their children [71,74,74,76,77].

The experience of incomprehension

The experience of incomprehension and of feeling unheard is central to the suicidal process for all the participants: before the suicide attempt, in the precipitating factors, and while in care [42,43,46,47,49–53,55–60,62,65,66,68–72,74,76–80,82,83,85].

The youth do not feel understood [43,49–52,55,57,58,62,66,68,70,83]. The family's or peer group's failure to hear leads to the suicidal behaviour [43,49–52,55–58,60,62,66,68,70,83].

The parents, for their part, do not understand [71,72,74,76,77,80]. Faced with the violence of the act, their immediate reaction is denial, distancing from what frightens them [71,74,80], or shock or stupefaction that prevents any reaction

[71,80]. Later, they ask themselves numerous questions that remain unanswered [72,74,76,77].

Getting better requires that the youth be understood by those around him or her [43,49,56,58,65], including by empathetic professionals [62,65,66,68], supported by family or a therapeutic setting [46,47,49,51,53,58,59,62,65,66,68–70,83]. Professionals underlined the difficulties of empathy and the contradictory positions, which are a barrier to care [42,78,79,82,85].

The social and cultural experience

The two subthemes of this superordinate theme describe the socio-cultural dimension of suicide. The peer group, the cultural group, and the society, by the ways they accept or reject youth in distress and their families, play a role in the process of suicidal behaviour and in its management.

Failure to fit into the group

Both the youth and their parents underlined the difficulties of belonging to the peer group, to the cultural group, or more broadly, to the social group. Young people associate this failure to fit in with shame, guilt, and anger — and parents often corroborate these feelings [43–45,48–61,63,65–67,70,72,76,77,84].

The self-esteem of young people is based on numerous standards and values — religious, cultural, or of the ideal family structure, school success, beauty, health, or sexuality [43–45,49,50,52–54,57–61,65–67,70,84]. Inability to meet these standards provokes different reactions: shame about the inability to cope and the experience of stigmatisation [44,52–54,56,61,65,67,84], guilt [48,49,52,56,61,67] or anger against others [45,49,50,54]. These emotions can be so strong that young people can consider suicide a conceivable response [50]. Some situations — those of LGBT youth, as well as cultural or religious minorities — are examples of these difficulties [51,55,61,63,65,84].

Parents repeat what their children have said and report this feeling of failure. The shame of what they did or did not do, of their performance in school, of what has happened, of what they cannot accept, of their physical appearance, of who

they are or cannot succeed in being [72,76] — all these play a role in the escalation of their distress [77].

Sociocultural facilitators and barriers to suicide and its management

The sociocultural environment, religious beliefs, representations of death, community groups: all of these are levers that facilitate or obstacles that block effective care [42,49,51–54,60–63,65–67,69,71–73,77–80,82,83,85].

Religious beliefs are often a protective factor: the principal religions preach that suicide is forbidden, an offense to God, for humans have a duty to take care of themselves [42,52,53,85]. But this ban can also lead to the exclusion of those who are suffering [42,52], and the absence of any consideration of their suffering in their religious beliefs can be "*a reason for engaging in suicidal behaviour*" [42]. In some contexts, this difference in the influence of religion may be more marked according to gender and may protect girls more than boys [67].

Media representations of self-harm behaviour play an important role in suicidal actions [77,82]. According to some healthcare professionals, the media may promote an idealised image of rebellious youth, including those who rebel by suicide [82].

Each group of participants raised the question of the right to die or of whether it is forbidden, an issue underlain by ethical, philosophical, and cultural considerations [42,49,52–54,61,63,65–67,78–80,82,85].

Stigmatisation of distress and of suicidal ideas block access to care for young people and their families [60,67,71–73]. Families that have experienced a child's suicide — attempted or completed —do not allow themselves to talk about it. In particular, in some cultures, suicide is a trauma that affects the entire family and is transmitted from generation to generation [85].

But there are organisations and structures in society that promote care: religious and organisational support for the parents [72] and peer networks for youth [51,53,62,69,83].

Discussion

This qualitative synthesis of 44 studies questioning youthful suicide attempters, their parents, and their healthcare providers enabled us to identify three superordinate themes which describe their experience: individual experience, relational experience, and social and cultural experience. One result is transversal at the heart of each group's experience: incomprehension is a barrier to effective care. The violence of the message of a suicidal act and the fears associated with death lead to incomprehension on all sides and interfere with the capacity of both family members and professionals to empathize with the young person.

This incomprehension is present in most of the themes: difficulty in understanding oneself and in coping with one's individual experience; difference, incomprehension, and rejection in relational experiences; and shame, guilt, and inability to fit into the social or cultural group. The suicidal act, frightening and shocking, reinforces this incomprehension. The family expresses doubts, calls itself into question, but also blames the youth: how could he have done this to us? Professionals cannot make sense of the act. The will to die is unthinkable.

When youth behave suicidally, they impose the violence of their act on others, on family, friends, and on the healthcare providers who support them. The suicide attempt acts out feelings of anger, hatred, and vengeance toward the other: others who are not sufficiently present, did not listen enough, did not understand enough. It is then very hard to be empathetic toward a youth who treats you so aggressively. It is difficult to empathize, identify, with distress that is expressed as violence — violence directed at the family, friends, and professionals. This is the primary observation of this meta-synthesis: everyone experienced and expressed great difficulty in identifying with the distress of these youths. Family members reacted by denial, by distancing themselves from what frightens them. Healthcare providers described their difficulties in being empathetic and asked for assistance, usually framed as a desire for specialised training. The violence addressed to them as the other stupefies their capacity to understand, listen, and empathize.

The response of the sociocultural group to suicidal behaviour is also most often a response to this violence: criminal prosecution for suicidal behaviour, allowed in some countries, is intended to protect the group. The moral condemnation that some participants report, sometimes transmitted between generations, is also intended to limit these actions perceived as aggressive. The results show this to be particularly true in Asia, Africa, and among men in South America [52,54,57,67,84,85]. Religion, when it condemns suicide, protects the group from violence to the detriment of any consideration of the individual's distress. The group is thus protected from the distress linked to loss and mourning, but also and especially from the violence driven by the suicidal behaviour. In the West, finally, the medicalization of suicidal behaviour seeks to give a meaning, labelled in terms of pathology, to this violence [7,43,61].

How can we support a family member whose distress is unthinkable? How can we treat someone when our capacity of empathy is dumbfounded? How can we escape this relation impasse? This is the primary issue in caring for these youths and their families.

Implications for practice

It is important to rethink the relationships between doctors, parents, and young patients in the context of attempted suicide. The difficulties of empathy toward these young people interfere both with care and support by their families. The issue in treatment is to witness this violence so that the patient feels understood and heard. The objective of course is to prevent recurrence: when the violence of the message is not heard in treatment, the suicidal potential remains present.

One pathway for envisioning the therapeutic relationship with these patients may be in the concept of intersubjectivity and in the conceptualisation of a "third space" [86–91]. The concept of intersubjectivity envisions the construction of self through the experience of a relationship with another and of interactions with another. The therapeutic relationship can thus be thought of as a place of exchange and construction, as "*two autopoietic human beings with embedded nervous systems that are engaged within a shared environment, the intersubjective third space, from which new therapeutic possibilities can arise*"[91]. The model of

the third space has been envisioned in the care of chronically suicidal patients [87]. It suggests treatment ideas borrowed from the treatment of patients with chronic pain. These situations may promote the appearance of negative empathy based on experiences of hostility, prejudice, and stigmatization [90]. The third space restarts communication in different ways, by sharing the experiences of patients and professionals and makes it possible to combat the professionals' rejection and negative feelings, thus promoting care.

From a relational perspective, the creation of a third space gives the parties the opportunity to create a respectful interpersonal relationship [87]. Professionals must make a commitment to share their representations of patients' suicide behaviour. The objective here is to establish relative equity within the relationship, so that patients feel understood and able to share their experience [90]. The third space is a staging of the active rapprochement of patients and professionals. The latter share with the patients important representations of the suicidal behaviour and also of the loss of their ability to contain the patient's experience. This rapprochement allows patients to let themselves share this experience.

From social and cultural perspectives, work is necessary on the representations of suicidal behaviour conveyed in the medical world. Numerous disciplines, especially the social sciences, consider suicide, which can thus be envisioned in a collective dimension, as a social fact or as influenced by cultural phenomena [92–96]. The current trend is towards the medicalization of our understanding of suicidal behaviours [7]. Nonetheless, these behaviours are not solely related to medicine and pathology: the psychiatric comorbidities of suicide vary greatly as a function of social, cultural, and educational contexts [7]. Treatment of adolescents with suicidal behaviour and their families should always include multidisciplinary management, including social workers and people with training in education [7,97]. A better understanding and management of suicidal behaviour requires apprehending it in all its psychological, social, and cultural complexity [20].

Implications for research

This synthesis has enabled us to examine the perspectives of the principal protagonists of care for young people who take suicidal actions. The parents' perspective has principally focused on the study of families in which those acts were successful. It appears important to develop research about the parents of youth whose attempts failed: what changes does this failed act induce in a family?

The media's fascination with suicide has been studied widely, and youth are particularly exposed [3,98–100]. But media are also powerful tools that enable the circulation of representations. Research must also examine how to use the media as a tool to share representations around suicide.

Finally, more in-depth study is needed of the representations of both the death of a young person and a self-inflicted death, by the integration of the social, anthropological, and philosophical dimensions. The sociological literature on this question (see [95,101,102]) has difficulty associating the individual and societal levels. It is essential to integrate these different perspectives to be able to propose an explanatory model of suicide among the young on which proposals for care can be based.

Strengths and limitations of this review

This review integrates the experience of distress and care of the principal stakeholders participating in the care of youth suicide: suicidal young people, their families, and healthcare professionals. It is based on a rigorous method, tested in medical research [25–27,103–106] and meets the criteria of the principal protocol used in qualitative research (ENTREQ). A systematic review of the principal search engines in this domain enabled us to select a large body of articles. The synthesis is based on the analysis of 44 studies, globally of good quality, published in peer-reviewed journals. The themes proposed here are widely found in the literature. They describe the experience of nearly 900 participants, providing a perspective much larger than any of the initial studies.

The data from the qualitative meta-synthesis includes participants for whom only partial data are available, as well as the interpretations of the researchers

whose studies we included. Any generalisation should be cautious. Nonetheless the triangulation of numerous points of view, different methods, and different cultural areas, is a strength that promotes the emergence of theoretical explanatory proposals.

Although the synthesis includes articles from diverse cultural areas, the restriction to articles in either English or French limits the cultural perspectives. For the future of this method, it would be useful to develop methods that would allow the inclusion of data from cultural areas that publish only rarely or even never in English.

The articles included provide only a limited look at the influence of gender on the experience of suicidal behaviour. Nonetheless, other types of studies have explored the role of gender with important results (see for example [107–110]). In the future, qualitative studies on suicidal behaviour should consider its role.

The results of the studies are particularly homogeneous, which in qualitative research is a limitation, for this field seeks to shed light on the question through new perspectives. This observation has already been noted in some meta-syntheses of adult suicide attempters [30,32]. The difficulties related to thinking about death and the message of the suicide may explain this homogeneity. Qualitative research involves the subjective participation of researchers. The question of suicide seems to be difficult for researchers to envision, just as it is for participants to think about.

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Annexes

Table S1. ENTREQ statement

N#	Item	Guide and description	Report on page #
1	**Aim**	State the research question the synthesis addresses.	#3
2	**Synthesis methodology**	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	#4
3	**Approach to searching**	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	#4
4	**Inclusion criteria**	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	#4-5
5	**Data sources**	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	#5 Table 1 Flowchart
6	**Electronic Search strategy**	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	#5 Table 1 Flowchart File 1
7	**Study screening methods**	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	#5 Flowchart
8	**Study characteristics**	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	#7 Table 3
9	**Study selection results**	Identify the number of studies screened and provide reasons for study exclusion (e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory	#5 Table 1 Flowchart

		development).	
10	**Rationale for appraisal**	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	#5,7 Table 2 File 2
11	**Appraisal items**	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	#5,7 Table 2 File 2
12	**Appraisal process**	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	#5
13	**Appraisal results**	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	#7 Table 2 File 2
14	**Data extraction**	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	#5-6
15	**Software**	State the computer software used, if any.	NC
16	**Number of reviewers**	Identify who was involved in coding and analysis.	#5-6,16
17	**Coding**	Describe the process for coding of data (e.g. line by line coding to search for concepts).	#5-6
18	**Study comparison**	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	#5-6
19	**Derivation of themes**	Explain whether the process of deriving the themes or constructs was inductive or deductive.	#5-6
20	**Quotations**	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	Table 5
21	**Synthesis output**	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	#7-15

Table S2. Complete search strategy. Performed on July 1, 2013 (updated on May 31, 2014).

Medline (Pubmed) (1990-2013, English) (Updated 2013-May 2014)
((MH "Suicide+") OR (MH "Suicidal Ideation") OR (MH "Suicide, Attempted") OR ("suicide Attempts") OR ("suicide") OR ("attempted suicide") OR ("suicidal ideation") OR ("suicide ideation") OR ("suicidal behaviour") OR ("youth suicide") OR (MH "Self mutilation") OR (MH "Self-Injurious Behavior+") OR ("overdose") OR ("self poison*") OR ("self inflict*") OR ("self harm*") OR ("self cut*") OR ("self destruct*") OR ("self-injur*") OR ("self mutilate*")) AND ((MH "Adolescent") OR (MH "Young Adult") OR (MH "Adolescent Psychology") OR (MH "Adolescent Psychiatry") OR (MH "Adolescent Behavior") OR (MH "Adolescent Development") OR ("teenagers") OR ("teens") OR ("adolescence") OR ("adolescent") OR ("adolescents") OR ("young adult") OR ("young")) AND ((MH "Qualitative research") OR (MH "Nursing Methodology Research") OR (MH "Focus Groups") OR (MH "Observation") OR ("qualitative research") OR ("qualitative study") OR ("qualitative method")) AND ((MH "Knowledge")OR (MH "Psychology") OR (MH "Self Concept") OR (MH "Adolescent Psychiatry") OR (MH "Attitude") OR (MH "Perception") OR (MH "Self Concept") OR ("perception") OR ("attitude") OR ("feeling") OR ("knowledge") OR ("belief") OR ("view") OR ("perspective") OR ("opinion") OR ("experience") OR ("image") OR ("self concept") OR ("barrier*") OR ("psycholog*") OR ("psychiatry")) **[194 results]**
PsycINFO (1990-2013, English) (Updated 2013-May 2014)
((DE "Suicide+") OR (DE "Attempted Suicide") OR (DE "Suicidal Ideation") OR ("suicide Attempts") OR ("suicide") OR ("attempted suicide") OR ("suicidal ideation") OR ("suicide ideation") OR ("suicidal behaviour") OR ("youth suicide") OR (DE "Self mutilation") OR (DE "Self Injurious Behavior") OR (DE "Self Destructive Behavior") OR ("overdose") OR ("self poison*") OR ("self inflict*") OR ("self harm*") OR ("self cut*") OR ("self destruct*") OR ("self-injur*") OR ("self mutilate*")) AND ((DE "Adolescent Psychiatry") OR (DE "Adolescent Psychology") OR (DE "Adolescent Psychopathology") OR (DE "Adolescent Psychotherapy+") OR (DE "Adolescent Attitudes") OR (DE "Adolescent Development") OR ("teenagers") OR ("teens") OR ("adolescence") OR ("adolescent") OR ("adolescents") OR ("young adult") OR ("young")) AND ((DE "Qualitative Research") OR (DE "Interviews") OR (DE "Intake Interview") OR (DE "Interview Schedules") OR (DE "Psycho diagnostic Interview") OR (DE "Grounded Theory") OR (DE "Observation Methods") OR (DE "Ethnography") OR (DE "Discourse Analysis") OR (DE "Content Analysis") OR (DE "Phenomenology") OR (DE "Philosophies") OR (DE "Constructivism") OR (DE "Hermeneutics") OR (DE "Narratives") OR (DE "Biography") OR (DE "Life Review") OR (DE "Storytelling") OR ("qualitative research") OR ("qualitative study") OR ("qualitative method")) AND ((DE "Attitudes") OR (DE "Knowledge (General)") OR (DE "Psychology") OR ("perception") OR ("attitude") OR ("feeling") OR ("knowledge") OR ("belief") OR ("view") OR ("perspective") OR ("opinion") OR ("experience") OR ("image") OR ("self concept") OR ("barrier*") OR ("psycholog*") OR ("psychiatry")) **[169 results]**
CINAHL Plus - Cumulative Index to Nursing and Allied Health Literature (EBSCO Publishing) (1990-2013, English) (Updated 2013-May 2014)
((MH "Suicide+") OR (MH "Suicide, Attempted") OR (MH "Suicidal Ideation") OR ("suicide Attempts") OR ("suicide") OR ("attempted suicide") OR ("suicidal ideation") OR ("suicide ideation") OR ("suicidal behaviour") OR ("youth suicide") OR ("overdose") OR ("self poison*") OR ("self inflict*") OR ("self harm*") OR ("self cut*") OR ("self destruct*") OR ("self-injur*") OR ("self mutilate*") OR (MH "overdose") OR (MH "Self-Injurious Behavior") OR (MH "Injuries, Self-Inflicted")) AND ((MH "Adolescence+") OR (MH "Adolescent Care") OR (MH "Adolescent Health") OR (MH "Adolescent Psychiatry") OR (MH "Adolescent Psychology") OR (MH "Adolescent Development") OR (MH "Adolescent Behavior") OR ("teenagers") OR ("teens") OR ("adolescence") OR ("adolescent") OR ("adolescents") OR ("young adult") OR ("young")) AND ((MH "Qualitative Studies+") OR (MH "Focus Groups") OR (MH "Interviews+") OR (MH "Narratives") OR (MH "Observational Methods+") OR (MH "Discourse Analysis") OR (MH "Thematic Analysis") OR (MH "Semantic Analysis") OR (MH "Field Studies") OR (MH "Audiorecording") OR (MH "Constant Comparative Method") OR (MH "Content Analysis") OR

(MH "Field Notes") OR (“qualitative research”) OR (“qualitative study”) OR (“qualitative method”)) AND ((MH "Attitude+") OR (MH "Knowledge+") OR (MH "Self Concept+") OR (MH "Psychology+") OR (“perception”) OR (“attitude”) OR (“feeling”) OR (“knowledge”) OR (“belief”) OR (“view”) OR (“perspective”) OR (“opinion”) OR (“experience”) OR (“image”) OR (“self concept”) OR (“barrier*”) OR (“psycholog*”) OR (“psychiatry”))

[593 results]

Embase (Ovid) (1990-2013, English) (Updated 2013-May 2014)

(‘suicide'/exp OR ‘suicide attempt'/exp OR ‘suicidal behavior'/exp OR ‘suicidal ideation'/exp OR (suicide attempts) OR (suicide) OR (attempted suicide) OR (suicidal ideation) OR (suicide ideation) OR (suicidal behaviour) OR (youth suicide) OR ‘automutilation’/exp OR (self mutilat*) OR (overdose) OR (self poison*) OR (self inflict*) OR (self harm*) OR (self cut*) OR (self destruct*) OR (self injur*)) AND (‘adolescent'/exp OR ‘child behavior'/exp OR ‘adolescent development'/exp OR ‘adolescent disease'/exp OR ‘adolescent health'/exp OR ‘child psychiatry'/exp OR ‘child psychology'/exp OR (teenagers) OR (teens) OR (adolescence) OR (adolescent) OR (adolescents) OR (young adult) OR (young)) AND ('qualitative research'/exp OR 'narrative'/exp OR 'observational study'/exp OR 'thematic analysis'/exp OR 'content analysis'/exp OR 'constant comparative method'/exp OR (qualitative research) OR (qualitative study) OR (qualitative method)) AND ('attitude'/exp OR 'knowledge'/exp OR 'psychology'/exp OR 'self concept'/exp OR (perception) OR (attitude) OR (feeling) OR (knowledge) OR (belief) OR (view) OR (perspective) OR (opinion) OR (experience) OR (image) OR (self concept) OR (barrier*) OR (psycholog*) OR (psychiatry))

[266 results]

SSCI – Social Sciences Citation Index (1990-2013, English) (Updated 2013-May 2014)

(“suicide attempts” OR “suicide” OR “attempted suicide” OR “suicidal ideation” OR “suicide ideation” OR “suicidal behaviour” OR “youth suicide” OR “Self mutilate*” OR “Self Injur*” OR “overdose” OR “self poison*” OR “self inflict*” OR “self harm*” OR “self cut*” OR “self destruct*”) AND (“teenagers” OR “teens” OR “adolescence” OR “adolescent” OR “adolescents” OR “young adult” OR “young”) AND (“case study” OR “constant comparative” OR “content analysis” OR “descriptive study” OR “discourse analysis” OR “ethnography” OR “ethnographic” OR “Focus group” OR "focus groups" OR “grounded theory” OR “interview*” OR “narrative*” OR “observation*” OR “qualitative method*” OR “qualitative research” OR “qualitative study” OR “thematic analysis” OR “semi-structured” OR “in depth”) AND (“Perception” OR “Attitude” OR “Feeling” OR “Knowledge” OR “Belief” OR “View” OR “Perspective” OR “Opinion” OR “Experience” OR “Image” OR "self concept" OR “barrier*” OR “psycholog*”)

[582 results]

Table S3. CASP (Critical Appraisal Skill Program) results.

***Legend*: T: Totally met; P: Partially met; N: Not met; ?: Unclear**

	CASP	Anderson et Al. (2000) (1)	Anderson et Al. (2003)(2)	Anderson et Al. (2005)(3)	Anderson et al. (2012)(4)	Bennet et Al. (2003)(5)	Baker et Fortune (2008)(6)	Beekrum et al. (2011)(7)	Bennett et al (2002)(8)	Bergmans et al. (2009)(9)	Bostik et Everall (2006)(10)	Bostik et Everall (2007)(11)	Daly et Al. (2005)(12)	Diamond et al. (2011)(13)	Everall (2000)(14)	Everall et al. (2005)(15)	Everall et Bostik (2006) (16)	Everall et Altrows (2006) (17)	Fenaughty et Harré (2003)(18)	Greidanus et Everall (2010)(19)	Herrera et al. (2006)(20)	Jo et al. (2011)(21)	Jordan et al. (2012)(22)	Keynavara et al. (2011)(23)
1	Was there a clear statement of the aims of the research?	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	P
2	Is a qualitative methodology appropriate?	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	P	T	P	T	T
3	Was the research design appropriate to address the aims of the research?	T	T	T	T	T	T	T	T	T	T	T	T	T	T	P	T	T	T	P	T	P	T	T
4	Was the recruitment strategy appropriate to the aims of the research?	P	P	T	T	T	P	T	T	T	T	T	T	T	T	P	T	P	T	N	T	P	T	P
5	Were the data collected in a way that addressed the research issue?	T	T	T	T	N	P	T	T	T	T	T	T	T	T	T	T	T	T	T	T	P	T	T
6	Has the relationship between researcher and participants been adequately considered?	T	T	P	T	T	P	N	N	T	T	T	N	T	T	N	T	T	N	N	T	P	T	N
7	Have ethical issues been taken into consideration?	N	N	N	T	T	T	T	N	T	T	T	T	T	P	T	T	T	T	T	T	T	T	T
8	Was the data analysis sufficiently rigorous?	T	T	P	P	P	P	P	P	T	T	T	T	T	T	N	T	P	P	T	T	P	T	N
9	Is there a clear statement of findings?	T	T	T	T	P	T	N	P	T	T	T	P	T	T	N	T	N	P	N	T	P	T	N
10	How valuable is the research?	T	T	T	T	P	T	T	P	P	T	T	P	T	T	T	T	P	T	P	T	P	T	P

	CASP	Maple et Al. (2007)(24)	Maple et Al. (2010)(25)	Medina et Luna (2006)(26)	Medina et al. (2011)(27)	Lindqvist et al. (2008)(28)	Nirui et Al. (1999)(29)	Osafo et Al. (2011)(30)	Orri et Al. (2014)(31)	Owens et Al. (2008)(32)	Paulson et Everall (2003)(33)	Rodham et Al. (2007)(34)	Shilubane et al. (2012)(35)	Sinclair et Al. (2005)(36)	Slovak et Al. (2012)(37)	Tallaksen et Al. (2013)(38)	Törnblom et Al. (2013)(39)	Sun et Hui (2007)(40)	Walsh et al. (1997)(41)	Wasserman et al. (2008)(42)	Yang (2012)(43)	Zayas et al. (2010)(44)
1	Was there a clear statement of the aims of the research?	T	P	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	P
2	Is a qualitative methodology appropriate?	T	T	T	T	T	T	T	T	T	T	T	P	T	T	T	T	T	T	T	T	T
3	Was the research design appropriate to address the aims of the research?	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	P	T	T	P
4	Was the recruitment strategy appropriate to the aims of the research?	P	N	T	T	T	T	T	T	P	T	T	P	T	T	T	N	T	T	T	T	T
5	Were the data collected in a way that addressed the research issue?	T	P	T	T	T	T	T	T	P	T	T	P	T	T	T	T	T	T	T	T	P
6	Has the relationship between researcher and participants been adequately considered?	P	N	T	T	T	P	T	T	P	T	T	N	P	P	T	T	T	T	P	T	P
7	Have ethical issues been taken into consideration?	N	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	T	N	T	N
8	Was the data analysis sufficiently rigorous?	T	N	T	P	T	P	T	T	P	P	T	N	P	T	T	T	T	T	P	T	P
9	Is there a clear statement of findings?	T	N	T	P	T	T	T	T	T	T	T	N	P	P	T	T	T	T	P	T	T
10	How valuable is the research?	T	P	T	T	P	T	T	T	P	P	T	P	P	T	T	T	T	T	P	T	T

File S4. List of the 124 papers excluded in the last step of the review

1) Articles excluded for methodological issues (4)

Biddle, L., Cooper, J., Owen-Smith, A., Klineberg, E., Bennewith, O., Hawton, K., … Gunnell, D. (2013). Qualitative interviewing with vulnerable populations: Individuals' experiences of participating in suicide and self-harm based research. Journal of Affective Disorders, 145(3), 356–362. doi:10.1016/j.jad.2012.08.024

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2) Articles excluded for thematic issues (8)

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3) Articles excluded for ineligible participants (112)

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Article 3 - Bilan des avancées méthodologiques au sujet des métasynthèses dans le champ du soin psychique de l'adolescent

Le troisième article est un article méthodologique qui propose un résumé de l'état des lieux de la littérature des métasynthèses qualitatives en recherche médicale et une description détaillée de la méthode que nous avons mis au point au cours de notre travail de thèse. Cet article a été soumis pour publication en juillet 2016 à la revue *European Child and Adolescent Psychiatry*.

A l'issue de notre deuxième métasynthèse, notre méthode est plus aboutie en termes d'adaptation aux problématiques psychiatriques adolescentes. Nous avons ajouté un certains nombres de critères issus du domaine des méta-analyses – notamment la systématisation de la recherche et de l'inclusion d'articles – de même que de nombreux critères issus du monde qualitatif – subjectivité assumée, propositions théorique, rigueur dans la description de la méthode.

Cet article permet d'inscrire notre méthode au sein du courant de réflexion sur la métasynthèse en recherche médicale. Il est l'aboutissement du travail réalisé au cours des précédentes études. L'analyse des dernières données de la connaissance méthodologique a fait naître de nombreux questionnements nécessitant une prise de position. La réflexion et l'expérience acquise au cours des travaux nous permet de proposer et d'assumer nos choix et de les justifier au regard des principales publications scientifiques.

Notre propos s'attache tout d'abord à inscrire notre méthode dans la spécificité de la recherche psychiatrique. L'importance du développement des études qualitatives dans le champ de la psychiatrie rend cette méthode nécessaire. Nous proposons alors une description de notre protocole, étape par étape. L'intérêt de publier un protocole détaillé est double : dans un constant objectif de rigueur, la réflexivité indispensable en recherche qualitative impose aux chercheurs de détailler chaque étape de la recherche ; dans un important souci d'expansion de la recherche qualitative, le caractère pédagogique d'une telle publication est

indéniable. Mais cet article est plus qu'un simple protocole : pour chaque étape, une synthèse des données de la science est proposée avant la description de notre méthode. Chaque point de méthode est ainsi réfléchi et discuté, et chaque décision est justifiée.

La discussion permet d'affirmer l'importance des métasynthèses en recherche, leur rigueur et leur valeur scientifique.

Synthesizing qualitative literature in adolescent psychiatry: lesson learnt

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Title: Synthesizing qualitative literature in adolescent psychiatry: lesson learnt

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Abstract

Background: Metasynthesis — the systematic review and integration of findings from qualitative studies, somewhat analogous to the meta-analyses of quantitative studies — is an emerging technique in medical research that can use many different methods. Nevertheless, the method must be appropriate to the specific scientific field in which it is used. No specific method for metasynthesis in psychiatry currently exists. The objective is to describe the steps of a metasynthesis method adapted from thematic synthesis and phenomenology to fit the particularities of psychiatric research and that is simple, rigorous, efficient, easy to share and teach, and able to handle a large amount of data into a synthesis that can have immediate clinical implications. **Method**: The method is described in six steps: define the research question and the inclusion criteria; select the studies; assess their quality; extract and present the formal data; analyze the data; and express the synthesis. **Conclusions**: This clearly structured method makes it possible to achieve a high level of understanding and to derive immediate therapeutic implications. It meets standard qualitative criteria for rigor: triangulation, reflexivity, clear exposition of the procedures used for data collection and analysis, attention to negative cases, fair dealing, and respondent validation. **Keywords**: qualitative research, metasynthesis, meta-ethnography, psychiatry

Background

The use of qualitative research is proliferating in medical research [1–3], and particularly in the psychiatric field [4–6]. This methodology is traditionally used to increase understanding of a phenomenon and to elicit the links between participants' attitudes toward health, their individual characteristics, and their environment. Over the past two decades, numerous studies in the field of psychiatry and adolescent psychiatry have used qualitative protocols [7–15]. Some have expressed concern, however, that because qualitative studies are often conducted in isolation and rarely used to contribute to practical knowledge, they do not play a significant role in the movement toward evidence-based medicine [16–18]. To alleviate this concern and enable qualitative work to contribute to this movement, an increasing number of teams have worked to develop and apply synthesis methods to these data, in order to capture the increasing volume of qualitative research, to facilitate the transfer of knowledge to improve healthcare, and to bring together a broad range of participants and descriptions [19,20].

Metasynthesis was first developed in the social sciences [21,22] and then successfully implemented in the health sciences [23]. The first metasynthesis in health care was published in 1994 by Jensen & Allen [24], and the number of qualitative syntheses has been increasing rapidly since the 2000s [17,25–28]. Tong et al. (2012) counted 381 syntheses of qualitative research when they constructed their guidelines [29]. In the medical field, metasyntheses have been used mainly to address questions about patients' experiences of illness and care [30–35]. Before our work, however, only one metasynthesis had been published by a group of psychiatrists in any indexed journals [36]. There is an important need today for good metasyntheses that can allow clinicians and researchers to apprehend and apply qualitative results in the main fields of psychiatry.

Importance of qualitative research in psychiatry

The development of evidence-based medicine has led to the apparent hegemony of quantitative methods in psychiatric research, even though the use of qualitative research has not actually ever stopped. It has, indeed, increased substantially over the past decade [4] and been recognized as a valuable way to

"*obtain knowledge that might not be accessible by other methods and to provide extensive data on how people interpret and act upon their illness symptoms*" [36]. Qualitative methods are especially appropriate to answer the question of "*How does this come to happen?"* [4] and to understand a phenomenon "*from a 'native' point of view that above all emphasizes subjective meaning and experience"* [6]. What matters most is the respondent's perspective and the joint construction by the respondent and the researcher of a context-dependent, multiple, and complex reality [6]. In this respect, the qualitative approach is close to that of the psychiatrist: what is important is what the patient feels and experiences and what emerges during the interaction between the patient and the psychiatrist. This subjective co-construction is useful for building up local theory that helps to increase both of the important aspects of theory: individually relevant theory for clinical work and the general theory of a field, for research [6]. One of our qualitative metasyntheses, on adolescent obesity, exemplifies this dual role (see [37]). Our results suggest that adolescents may use food as a way to keep their parents (one or both) at a distance and thereby escape too close a relationship with them. This strategy fails, fails, however, as obesity ends up creating greater dependency on the parent. This result sheds useful light on a particular aspect of family relationships in this context and helps to generate both theory and knowledge.

Qualitative research offers a thick description (one that encompass all the complexity of the phenomenon, or behavior, or context) of a phenomenon and attempts to document the complexity and multiplicity of its experience [6]. Similarly, in their day-to-day clinical work, psychiatrists attribute great importance to complexity and try to place symptoms within the patient's history, in all of its intricate context — which again plays a crucial role in therapeutic choices. Qualitative research, from this vantage point, is complementary to quantitative research, focusing as it does on "real" or "contextualized" patients. This description is then used to construct theory [6]. For example, one of our recent qualitative studies focused on suicidal behavior and was based on interviews of young adults who had previously attempted suicide at least once [38]. Their narratives of these attempts focused on difficulties in experiencing their relationships to others and suggested that revenge sometimes explained

the attempt. The in-depth description of what we called a “relational impasse” allowed us to theorize that suicidal behavior represents a means of establishing a connection between one’s personal distress and important others, through the act itself. In this case, revenge transforms personal distress into a relational matter.

What is a metasynthesis?

The qualitative synthesis must be distinguished from a narrative review, which is a review of quantitative evidence in which the results from individual studies cannot statistically be pooled [19] or alongside meta-analysis. Metasynthesis, on the other hand, refers to a collection of different methods for systematically reviewing and integrating findings from qualitative studies [39,40]. As a quantitative meta-analysis can be understood as the statistical aggregation of statistical data, a qualitative metasynthesis might be conceptualized as a qualitative study that uses as its data the findings from other qualitative studies linked by their topic (the same or a related one) to cover it both in-depth and broadly [18]. As Kinn et al. noted (2013), while meta-analysis is interested in the causal relations within a particular intervention, metasynthesis "is more hermeneutic in nature and more theoretically ambitious in its aim to understand and explain a phenomenon" [39]. This research into primary research requires a systematic approach to collecting, analyzing, and interpreting results across multiple studies, to develop an overarching interpretation [21,40–43]. It involves going beyond the findings of any individual study to make the “whole into something more than the parts alone imply” [21].

This objective differentiates metasynthesis from narrative and or scoping reviews (systematic literature reviews) [30,41,44]: the difference lies “*in the systematic identification and charting of the key concepts in the papers being synthesized*” [44]. Traditional systematic reviews offer a coherent summary of the current literature on a topic. Some conclusions and clinical implications can be derived from it, but no interpretation is achieved. Metasynthesis, on the other hand, implies interpretation from the outset. The analysis relies on dissecting the data to form it into categories and themes that do not summarize the papers but describe the participants’ experiences and the interpretations of the authors of

these primary papers. The concepts of each study are compared one by one with the key concepts "in order to test the extent to which they endorse or contradict them" [44]. The discussion includes concepts from the social sciences and offers a third level of interpretation of the data: the first level is the construction of the participants themselves, i.e., the results of each individual study; the second level is the authors' interpretation and understanding of the participant narratives, i.e., the discussion and conclusion of each study; the third level is the conjoint interpretation of the first and second level given by the metasynthesis [17,18,30,39,43]. Nevertheless, the first-order constructs in some of these studies may be unreachable, because the authors may have chosen the participants' narratives as exemplars of their second-order interpretations [20].

Objectives of metasynthesis

Metasyntheses may have various objectives: by apprehending the full contribution of qualitative data on a topic, they contribute to the development of evidence-based care [17,23,44,45]; by going beyond the content of original studies, they allow authors to generate new insights, to reach a more profound theoretical understanding, and to transform these findings into more highly abstracted, comprehensive, formalized, and generalizable theoretical frameworks [17,18,23,26,29,30,39,46]. Metasynthesis is a valuable tool for obtaining and examining participants' meanings, experiences, and perspectives, both deeply and broadly, across healthcare contexts, to identify research gaps, to inform the development of primary studies, and to provide evidence for the development, implementation, and evaluation of health interventions [16,26,29,30].

Existing methods for synthesizing qualitative research

The number of methods for synthesizing qualitative research has grown in recent years [18,20,23,27,28,39–41]. Hannes et al. (2012) identified 20 different methods of qualitative synthesis [27], while Barnett-Page and Thomas (2009) distinguished 9 basic typologies, which they compared according to epistemological criteria that ranged from subjective idealism to naïve realism [41]. Some authors argue that a central distinction can be drawn between integrative methods, which aim to aggregate findings, and interpretive methods

intended to interpret these findings and develop conceptual understanding [30,47,48]. As Toye et al. (2014) point out, however, "*as description itself demands interpretation, it might be more useful to see aggregative and interpretive approaches as two poles on a continuum rather than two distinct approaches*" [20].

Finally, some authors classify the methods according to how they address the question of translation — i.e. how studies can relate to one another. The earliest authors of metasyntheses developed a method that they called 'meta-ethnography'. They identified three methods of translation: reciprocal translational analysis, refutational synthesis, and line-of-argument synthesis [17,20,21,30,41,43,44]. However, researchers' choice of method depends on their research question, intended synthesis output, philosophical position, context, and target audience [29].

Aims of this study

Despite the development of qualitative research in psychiatry, very little work has been done on adapting metasynthesis to the field of child and adolescent psychiatry [36,49–51]. Filling this gap has been one of the aims of our team since 2011. The team is composed of adolescentand child psychiatrists and psychologists from France and elsewhere (Italy, Chile, and Brazil) and focuses on developing qualitative research [37,38,52–54] and metasynthesis in adolescent psychiatry and related fields [55–59].

We have performed several metasyntheses to refine our method, adapting the thematic synthesis from Thomas and Harden (2008) to deal with new rigor with general as well as psychiatric issues [17]. We sought a method that would be simple, rigorous, efficient, easy to share and teach, and able to handle a large amount of data into a synthesis that could have immediate clinical implications.

In this paper, we present the steps of our method, discussing each step in light of the existing literature on metasynthesis, and demonstrating the rigor of this method and its value for adolescent psychiatric research, clinical practice, and care.

Conducting a metasynthesis

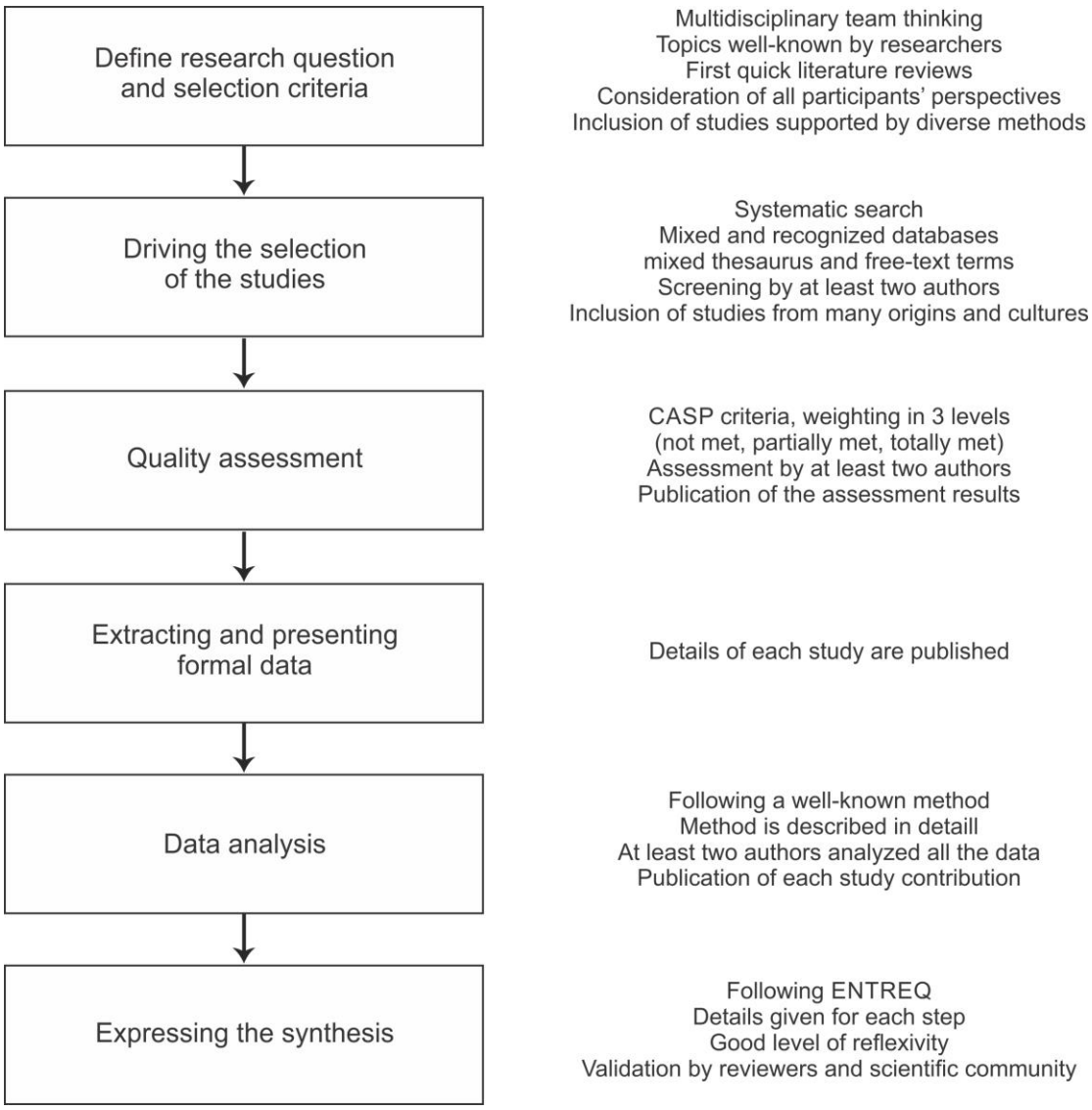
As the number of different methods for synthesizing qualitative research increases, some authors have begun to think about standard criteria for metasyntheses [19]. Subjectivity, however, is a key feature of qualitative research as well as of metasynthesis, and "*no two reviewers will produce exactly the same results*" [16]. The position of the Cochrane Collaboration, which has defined the gold standard for quantitative meta-analysis, is that a "*highly prescriptive form of standardization, which specifies only one way to conduct a QES* [Qualitative Evidence Synthesis]*, may be perceived as counterproductive by a substantial proportion of members of the qualitative research community*" [19,60,61]. We think that some steps of a metasynthesis, i.e., synthesizing translations and generating the line of argument, are highly subjective; indeed some authors describe them as ''*bricolage*'' [39,43]. Other steps, such as selecting and appraising the studies, are more objective and may be formalized. The most important step in the achievement of a high level of rigor is a thorough and detailed description of the method used [25]. Moreover, the researcher must work in collaboration [20,23,26,30,40,43], with researchers of diverse backgrounds [20,23]. A collaborative approach improves quality and rigor and subjects the analytical process to group reflexivity [26,43]. Finally, the research team should include members trained in qualitative synthesis as well as those expert in the topic being studied [30].

Our method is adapted from thematic synthesis [17], which combines and adapts approaches from both meta-ethnography and grounded theory [41]. It is based, in principle, on word-for-word coding, secondarily organized into descriptive and then analytical themes. This method meets our expectations: it was developed out of "*a need to conduct reviews that addressed questions relating to intervention need, appropriateness and acceptability – as well as those relating to effectiveness – without compromising on key principles developed in systematic reviews."* It "*produces an output that is directly applicable to policy makers and designers of interventions*" [41]. The most subjective step of the synthesis, the analysis, uses standard methods — grounded theory for Thomas and Harden (2008), phenomenological analysis in our work. This method can use computer

software for coding results and thus makes it possible to manage large quantities of data. It also appears to be the best method for drawing conclusions from heterogeneous studies [26,29,40,41,62]. It is not too restrictive and allows the research to be adapted appropriately when necessary [17]. Finally, it is a popular and well-known approach, successfully used in the medical field and probably more accessible to readers in medical fields than more narrative methods [27,32,62–64]. Each of these points is helpful for psychiatric research: user-friendliness for both researchers and readers; standardized in its most subjective steps but flexible, to make it adaptable to various patients or situations, such as children, patients with psychological disabilities or psychotic disorders, and to different researchers' backgrounds (e.g., phenomenology, psychology, or psychoanalysis). We applied the reporting guidelines in the ENTREQ statement [29].

In the sections that follow, we describe and analyze the different steps of the method (**Figure 1**), providing examples from two of our published works, one on the topic of adolescent obesity [65] and the other about suicidal behavior in young people [56].

Fig 1 – Flowchart of the study process



Define the research question and the selection criteria

Most reviewers consider defining the research question to be a crucial [16,20,29,30,44]. They must determine if a synthesis of the topic is useful and define their focus [16,20]. Typically it is a topic for which qualitative research can be informative [30] and that has already been explored by enough studies [48]. The question must be broad enough to be of interest but small enough to be manageable [16,30]. This step is dictated by the method chosen: how studies will be selected (and how many), and whether studies with diverse methodologies will be included. Thus, the inclusion and exclusion criteria help to define the

focus, in an approach that allows the researcher to narrow it if necessary [20]. In qualitative work, completeness of inclusion is not required, but complete representation of viewpoints is [16,29,30]. The authors may have to define a homogenous sample of participants. They must also choose whether or not to include different types of studies, such as those using phenomenological approaches, as well as those applying grounded theory or ethnography [18,39,40,42,46,66,67]. Some authors have pointed out that metasynthesis of data generated from multiple qualitative approaches has the potential to become a valuable form of triangulation [39,46,67]. Finally, authors may consider the question of the language and compromise between enlarging the representativeness of viewpoints and their understanding of the language [18,39].

We chose to address questions that were suitable qualitative questions, specifically, complex questions that concern not only medicine but also the social sciences, (e.g. obesity or suicide), have been widely explored by qualitative research, and for which new insights could be expected (because of the lack of effectiveness of current care, a need for more theory, and a need for elements to use in conducting prevention programs), and using different qualitative approach (e.g. phenomenology, grounded theory, or ethnography). As we focused on questions concerning the treatment process, we decided in almost all studies to include research concerning not only the population being treated, but also the healthcare professionals who care for these patients. We chose to include only qualitative research, because it remains unclear how to deal with mixed methods [30]. Although databases contain articles in different languages, we chose to include only articles published in English (as most studies are now published in English) and French (as it is our first language) [55,56].

Our 2015 metasynthesis about suicidal behaviors among young people in 2015 [56] illustrates these choices. We chose this subject because youth suicide is a major public health issue worldwide as well as a complex disorder that encompasses medical, sociological, anthropological, cultural, psychological, and philosophical issues. As we wanted to study the therapeutic relationship and barriers to effective care, we chose to include all studies that questioned youths,

parents, and healthcare professionals. A first screening of the literature showed us that optimal scope required a large range of ages, from 15- to 30-years-old. The common thread linking all these youths was the importance of their parents in their everyday life.

Study selection

As mentioned above, the scope of metasynthesis remains controversial, with some advocating a narrower, more precise approach, and others a broader, more inclusive stance [16,23,46,67]. Thus, the sampling of selected studies must be "*homogenous enough to confirm the findings, heterogeneous enough to ensure abstraction, yet not so abstract as to be meaningless*" [39] and "*not only large but wide*" [46] to ensure high degree of generalizability [30]. Finfgeld-Connett & Johnson (2013) differentiate expansive sampling (i.e., a search to build knowledge and theory should be iterative, from study to study) from exhaustive sampling (used for systematic and aggregative reviews) [48]. Some authors have stressed that the use of large samples presents a risk of reducing the rigor of the interpretative work [43,47]. Nevertheless, a growing number of reviewers opt for systematic searches, thereby resolving the question of data saturation [20,26,27,30,67]: including all the relevant literature on a topic ensures consideration of all data and knowledge on the question.

We privileged systematic searches since our method allowed large samples and because our target audience was the mental health community, which is accustomed to quantitative systematic reviews [20]. For the same reason, only journal papers were included, as most scientific data are published in this form [68].

A first selection of papers, as well as an existing literature review on the topic, served to specify some starting information and enable initial decisions, including the definition of the research question, specification of the scope and the inclusion criteria, and choice of keywords and databases for the electronic search. There is no consensus on using thesaurus terms [29,40,48,69–71], or about the most useful keywords for retrieving qualitative data in databases [72–74]. To ensure both sensitivity and sensitivity, we decided to use a combined approach of thesaurus terms and free-text terms. This technique maximizes the

number of potentially relevant articles retrieved and ensures the highest level of rigor [70]. Keywords were established during research team meetings, and were reported in the paper or as supplemental material for more clarity [25]. As each database has its own thesaurus terms, the keywords were specific for each one.

We used four clusters of keywords: (i) those that concern qualitative research (such as *qualitative research*, *interviews, focus groups,* or *content analysis*), (ii) those that concern perceptions and understanding, often called 'views' [68](such as *knowledge, perception, self-concept, feeling,* or *attitude*), (iii) those that concern the participants (gender, age, profession…), and (iv) those that concern the topic of interest (such as suicide, obesity, or anorexia nervosa).

Thus, the algorithm used in the Pubmed Web search in Lachal et al. (2015) [56] is provided in **Table 1**.

Table 1 – Algorithm used in the Pubmed Web Search in [56]

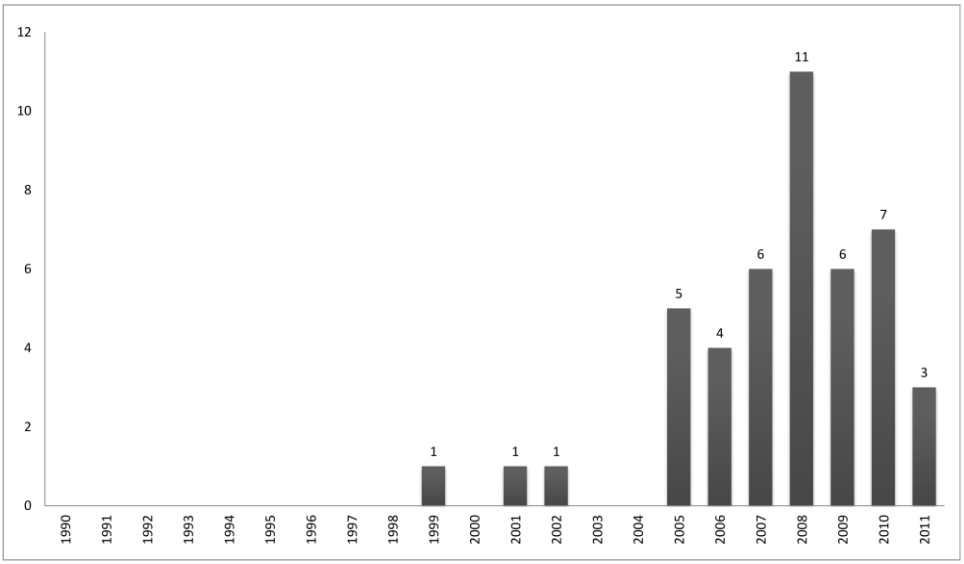
((MH "Suicide+") OR (MH "Suicidal Ideation") OR (MH "Suicide, Attempted") OR ("suicide Attempts") OR ("suicide") OR ("attempted suicide") OR ("suicidal ideation") OR ("suicide ideation") OR ("suicidal behaviour") OR ("youth suicide") OR (MH "Self mutilation") OR (MH "Self-Injurious Behavior+") OR ("overdose") OR ("self poison") OR ("self inflict*") OR ("self harm*") OR ("self cut*") OR ("self destruct*") OR ("self-injur*") OR ("self mutilate*"))*
AND
((MH "Adolescent") OR (MH "Young Adult") OR (MH "Adolescent Psychology") OR (MH "Adolescent Psychiatry") OR (MH "Adolescent Behavior") OR (MH "Adolescent Development") OR ("teenagers") OR ("teens") OR ("adolescence") OR ("adolescent") OR ("adolescents") OR ("young adult") OR ("young"))
AND
((MH "Qualitative research") OR (MH "Nursing Methodology Research") OR (MH "Focus Groups") OR (MH "Observation") OR ("qualitative research") OR ("qualitative study") OR ("qualitative method"))
AND
((MH "Knowledge")OR (MH "Psychology") OR (MH "Self Concept") OR (MH "Adolescent Psychiatry") OR (MH "Attitude") OR (MH "Perception") OR (MH "Self Concept") OR ("perception") OR ("attitude") OR ("feeling") OR ("knowledge") OR ("belief") OR ("view") OR ("perspective") OR ("opinion") OR ("experience") OR ("image") OR ("self concept") OR ("barrier") OR ("psycholog*") OR ("psychiatry"))*

Similar work was conducted to select the databases. After consulting reference papers [29,30,68–70,75,76] and metasyntheses on the subject [32,34,51], we decided to conduct the search in five electronic databases covering medical, psychological, social, and nursing sciences: MEDLINE, EMBASE, CINAHL, PsycINFO, and Social Science Citation Index (SSCI). Not long ago, CINAHL was the most important database for finding qualitative research [75], but as qualitative research proliferates in medical research, more and more qualitative papers are referenced in MEDLINE [68] and EMBASE. PsycINFO was a good database for finding qualitative papers with a psychological approach. We tested the Scopus database in our first systematic review [55] and obtained no nonduplicate articles from it.

These four main databases are also the ones recommended by the Cochrane Collaboration [60,77]. We decided to add SSCI to broaden and complexify the outlook with a sociological point of view. We followed recommendations published on MEDLINE [74], CINAHL [78], EMBASE [73], and PsycINFO [72] for choosing search terms. Finally, we decided not to use the methodological databases' filters for qualitative research, as these have undergone little replication and validation [29,69].

We decided to include papers published only in or after 1990. Two points impelled this decision: first, there was very little qualitative research in the health sciences before the year 2000, and even less before the 1990s (**Figure 2**). Secondly, we chose to consider as outdated research findings and results published more than 20 years ago were outdated, given the evolution of medical practices [46]. However, this choice must be adapted to the topic of metasynthesis.

Fig 2 - Distribution in time for papers included in [55]



The results of database searches were entered into a bibliographic software program (e.g., Zotero©, or Endnote©); both programs offer options for automatic removal of duplicates. Then, at least two authors independently screened all titles and abstracts and selected the studies according to our inclusion criteria. If the abstract was not sufficient, we read the full text. Disagreements were resolved during working group meetings. Full texts of potentially relevant papers were then examined, and a second selection was performed. At this phase, we also checked each paper's reference list looking for new papers we might have overlooked. In each of our studies, the final selection represented from 2 to 3% of the total initially obtained. This rate is consistent with the findings of other metasyntheses [30,69,70].

For clarity, the selection process was also presented in a flowchart (for an example, please refer to [56]).

Quality assessment of included studies

There is no consensus about whether quality criteria should be applied to qualitative research, or, for those who think they should be, about which criteria to use and how to apply them [16,17,19,20,25–27,29,30,40,41,47,67,77,79–83]. Questions remain about how to evaluate quality, why to evaluate it, and if this

evaluation is even possible [17,30]. Nevertheless, a growing number of researchers are choosing to appraise studies for metasyntheses. Hannes et Macaitis (2012) reported that the percentage of metasyntheses using a quality appraisal tool increased from 40% (1988-2004) to 72% (2005-2008) [27]. Some authors state that a good metasynthesis can no longer avoid this methodological step [17,29,40], especially if it seeks a readership of medical professionals, who are accustomed to the rigorous criteria of quantitative studies.

The reasons and methods for quality assessment fit into three general approaches: assessment of study conduct, appraisal of study reporting, and an implicit judgment of the content and utility of the findings for theory development [29]. Quality assessment should allow readers to make an informed judgment about the credibility, dependability, transferability, and confirmability of the studies; it should highlight the most effective qualitative method and facilitate a deeper understanding of the papers included [29]. Qualitative assessment should consider both methodological and conceptual insights, as well as the rigor and reflexivity of the reporting of the research process and the clarity of the concepts to be translated [83].

There is certainly not one best appraisal tool, but rather a wide choice of good ones [19]. The instruments reported to be used most often [20,26,27,29] are the Critical Appraisal Skills Program (CASP) [84], the Qualitative Assessment Review Instrument Tool (QARI) [85], and the Consolidated Criteria for Reporting Qualitative Research (COREQ) [86]. After we chose a specific instrument for our first review — the Spencer Framework [55,87], which had been used in other metasynthesis on the same subject — we changed to the CASP instrument for the next two [56,57]. CASP, which is the most frequently used instrument [26,27,29], addresses all the principles and assumptions underpinning qualitative research [29]. It is one of the instruments recommended by the Cochrane Collaboration [77] and has been used in several important thematic analyses of medical topics [30,88–92]. Finally, CASP is a simple tool that has been validated. As proposed by Boeije et al. (2011), we weighted our assessment by applying a three-point scale to each criterion (0= criterion not met; 1/P= criterion partially met; 2/T= criterion totally met) [45] (**Table 2**).

Table 2 – Evaluation of the quality of a study according to the Critical Appraisal Skill Programme (CASP)

Criteria	Totally Met	Partially Met	Not Met
1. Was there a clear statement of the aims of the research?			
2. Is a qualitative methodology appropriate?			
3. Was the research design appropriate to address the aims of the research?			
4. Was the recruitment strategy appropriate to the aims of the research?			
5. Were the data collected in a way that addressed the research issue?			
6. Has the relationship between researcher and participants been adequately considered?			
7. Have ethical issues been taken into consideration?			
8. Was the data analysis sufficiently rigorous?			
9. Is there a clear statement of findings?			
10. How valuable is the research?			

Another issue is how the quality appraisal affects the content of the metasynthesis [17,20,30,93]. Some authors suggest excluding low-quality studies [20,79]. Most authors, however, have thus far decided not to exclude any studies on the basis of the quality assessment. They argue that (i) excessively rigorous application of these criteria could be counterproductive, (ii) there is no empirical evidence justifying decisions to exclude studies, and (iii) insightful studies might be excluded [17,20,30]. Our response to this question is close to that of Toye et al. (2014): each study must be "*good enough*", that is, it must "*present a reflexive account of the research process that allows the reader to make a sound judgment about the authors' interpretation*" [20]. Qualitative methods deal mainly with the conceptual contribution, and all input is welcome [45]. Accordingly, we have not excluded any study from our metasyntheses [55,56]. Like other reviewers, however, we have noted that poorer quality studies tend to contribute less to the synthesis [17,21,23,45,94].

To enhance the rigor of the synthesis, reviewers may include a description of the criteria used to assess quality [67] and the results of this assessment [27,80]. This assessment should be performed and discussed by more than one researcher in each metasynthesis, and the details of the assessment should be

mentioned in the paper (usually in the results section) and perhaps expanded somewhat in the online supplemental material [45]. We used the National CASP Collaboration's description of the criteria [84].

Extracting and presenting the formal data

To understand the context of each study, readers need the formal data about each study: the number and type of participants in each study, its location, and the method of data collection and of analysis. These data must be extracted and presented in a way that enables readers to form their own opinions about the studies included.

We chose to present these data systematically, in a table with the following headings:

- Identification of the study
- Summary of the study's aim
- Country where the study took place
- Details about the participants: age, gender, type, and number
- Method of data collection (e.g., semistructured interviews or focus groups)
- Analysis method (grounded theory, phenomenology, thematic, etc.).

This table should be available for any reader, either directly in the paper or in the supplemental data (an example is provided in **Table 3**).

Table 3 – Part of the table of the main characteristics of the studies [56]

Study	Aims	Country	Nb[1]	Age[1]	Data coll.[2]	Analysis method
[95]	To explore young people's transitions towards resistance against future suicidal behaviours.	New Zealand	27	15-24	SSI	Discourse analysis
[96]	To identify common themes in answer to the question, "What was the experience of young adults who felt suicidal, made the decision, and attempted to end their lives?"	Canada	5	24-27	SSI	Phenomenology
[97]	To illustrate the role 3 major factors played in one teenager's experience of becoming and overcoming being suicidal: mental processes, cognitive development, identity formation, and autonomy-seeking.	Canada	1	20	SSI	Grounded theory
[98]	To develop an understanding of how adolescents and emerging adults experience and respond to emotions from the subjective perspective of previously suicidal participants.	Canada	50	15-27	SSI	Grounded theory
[99]	To gain further insight into the factors that may buffer L/B/G youth from suicidality and present a model integrating the known risk factors, with the resiliency factors that emerge.	New Zealand	8	18-25	SSI	Grounded theory

Data analysis

This step is probably the most subjective: its performance is highly influenced by the authors' backgrounds [29]. There are many ways to analyze, as many as there are authors. All researchers build on their personal knowledge and background for the analysis, sometimes described as *bricolage,* following Claude Levi-Strauss: "*the* bricoleur *combines techniques, methods, and materials to work on any number of projects and creations. Whereas a typical construction process might be limited by the history or original use of individual pieces, the* bricoleur *works outside of such limitations, reorganizing pieces to construct new meaning. In other words, unlike linear, step-by-step processes, the* bricoleur *steps back and works without exhaustive preliminary specifications"* [39] (see also [43,100]). The synthesis will inevitably be only one possible interpretation of the data [20], as it depends on the authors' judgment and insights [17,39]. In many ways, the synthesis "*reveals as much about the perspective of the synthesizer as it does about the substance of the synthesis*"(p.14) [21]. The reason for this variation is probably that the qualitative synthesis does not result simply from a coding process, but rather from the researchers' configuration of segments of coded data "*assembled into a novel whole*" [101].

The analysis comprises at least two stages: the synthesizer must first code the data in each study and then compare the codes between each study to create a synthesis. This latter stage corresponds to what Noblit and Hare called *translation* [21]. Synthesizing engages a process of combination and comparison of ideas, themes, and metaphors across the different studies while preserving the meaning from the original text insofar as possible. The final synthesis must explicitly describe how the whole is greater than the sum of its parts [39,67].

Numerous methods of synthesis have been developed, inspired largely by meta-ethnography [21]. Those that focus on units of meanings rather than on each word and that offer description that is categorical or thematic rather than narrative or comprehensive are more appropriate than others for synthesizing large collections of data [44]. We chose to follow the steps described by Thomas and Harden (2008) in their thematic synthesis method [17]. We think that this method is simple, effective, and clearly appropriate to qualitative papers in

psychiatry [17,41]. It applies inductive reasoning [42] and is adapted to thinner studies, which account for most of those in the medical filed [29]. The interpretive phenomenological approach that our research group applies is compatible with thematic synthesis.

Thomas and Harden (2008) describe a three-stage analysis: coding the text, developing descriptive themes, and generating analytical themes [17]. We consider that the entire paper, and not simply the results section, is part of the work of analysis, although this position is debated [23,86].

For us, the first step of this process involved carefully reading and rereading each study [16,17,20]. It is an active reading, with the intention of appraising, familiarizing, identifying, extracting, recording, organizing, comparing, relating, mapping, stimulating and verifying [43]. In other words, it is reading with "*the intention of collating a synthesizable set of accounts*" [43]. The second step was coding: at least two different researchers coded each part of the data, performing a line-by-line coding, close to the phenomenological analysis described by Smith et al. [102]. The use of software such as QSR's Nvivo was not routine in our research group, but this type of software may help in sharing a large amount of data [103] among the authors who perform the analysis. In the third step, the codes were grouped and categorized into a hierarchical tree structure. This step is very close to the translation work described by Noblit and Hare (1988) [21]. It involves comparing themes across papers to match themes from one paper with those from another while ensuring that each key theme captured similar themes from different papers. We obtained a list of descriptive themes very close to the data. Finally, in the last and most subjective step of the analysis, we generated analytical themes, which depended largely on the "judgment and insights of the reviewers" [17]. This step is very similar the development of third-order interpretations [30] and requires going beyond the content of original studies to achieve a higher level of interpretation and going beyond the descriptive synthesis to propose a more conceptual line-of-argument [17,30]. This work has two types of underlying aims. The first type may be theoretical, by enabling a higher level of comprehension of a phenomenon; in medical science, this may be to better describe and understand a pathology. The second type may be to

answer clinical questions about pathology and care directly. For example, why do problems in relationships hamper the care of pediatric obesity?

Expressing the synthesis

The original authors of meta-ethnography described three ways of synthesizing translation: (i) refutational syntheses, where findings contradict each other, (ii) reciprocal syntheses, where findings are directly comparable, and (iii) line-of-argument syntheses, where findings successively build a line of argument [20,21,43]. These types of synthesis must be discussed in relation to the different levels of interpretation. It is far from clear what the synthesizer must do to obtain first-, second-, and third-order themes [20,26]. Thomas and Harden (2008) say that third-order constructs are used to think and build a line of argument with first- and second-order themes [17]. We agree: throughout the analysis process, the authors build themes that take place in the *story* they are telling about the participant's experience. We did not define actual third-order themes; rather, third-order constructs helped us to build the synthesis into a line of argument. We sought to keep our results mainly descriptive and our discussions more interpretative, like those of the qualitative papers normally are.

The results are the themes that we developed in the analysis. Themes are said to be first-order and second-order, but because it is not always clear what first- and second-order constructs actually are [20], we decided not to distinguish them. Instead, we organized the themes into superordinate themes or axes of experiences, which are interpretations of the themes and can be considered third-order interpretations. **Table 4** presents an example from Lachal et al. (2015) [56].

Table 4 – Example of quotations from participants and authors of primary studies in [56]

Themes	Quotations from participants in primary studies	Interpretations of findings offered by authors
The experience of distress	Depressive symptoms: You're going to school, you're getting an education, but you're depressed. [96] Failure, defeat, self-disgust: I hated myself. [98] Getting better: I was really surprised at my will to live, to sort of keep going. [95]	Depressive symptoms: There is consistency in recognising the components we identify as despair. [98] Failure, defeat, self-disgust: She had a strong feeling of hatred toward herself; she saw herself as being fat, ugly, stupid, and blamed herself for difficulties in her life and in her family. [97] Getting better: Many participants emphasised 'thinking positively' about their lives and concerns as a useful component of problem solving.[95]
Self-control	Impression of losing control: I felt I had no control over my life. Whatever I did didn't matter. It was going to happen anyways. [98] Regaining control: I became quite social after coming out. I spose, yeah . . . I always just needed to constantly find that affirmation, it wasn't just something that I could say okay I've had enough, you know. I constantly needed that every day. ... and it was also about my whole, my self-esteem and confidence just totally went up every time as well, and if I stopped or something they'd just go down again. [99]	Impression of losing control: Thinking about suicide became a means of coping. [98] Regaining control: Leon's strategy similarly involved problem-focussed coping; he actively strengthened his social support network to secure self-esteem. [99]

The results prepare the framework for the discussion, which is the most interpretative part of the review, where we make hypothesis and proposals. We offer our understanding of the participants' experience. Both our presentation and our discourse are influenced by our aim: to answer clinical questions by suggesting specific actions or considerations for care; the discussion and the answers are intended to be useful for the readers of our article, as well as for us [20,26,30,44]. For example, in our synthesis of studies of child and adolescent obesity in 2013 [55], the principal conclusion of the discussion was that treatment must be preceded by a first meeting between the child, the doctor, and the parent, where each can exchange and share their representations of obesity. This conclusion is clear and simple for doctors who read the review to apply in clinical practice.

Each step of the work was performed in the team, to enhance the rigor of the results and subject the analytical process to group reflexivity [20,23,30,43,67]. In

each of our works, we also discuss the limitation of the findings. All studies have limitations, and discussing them enhances the credibility of the work, enabling readers to measure the importance and generalizability of the findings.

Discussion

This methodological paper is based on a broad-scale review of literature on the topic of metasyntheses. We have described the sequence of steps — very similar to those described by Thomas & Harden (2008) [17] —that we followed to perform two qualitative metasyntheses of psychiatric issues in adolescence. We have therefore used their term — thematic synthesis. Because we wanted both a medical and a psychological approach, we clarified the definition of some aspects of the method and modified or expanded others. For example, we opted to use a systematic search method and a weighted version of the CASP [84] to assess quality. Here we will discuss the scientific value of this type of synthesis, its scientific rigor, and the advantages it has for psychiatric research.

Most metasynthesis authors argue that these reviews achieve a third-order level of interpretation, that is, that they are more than the sum of their results. If, as we think, qualitative research can achieve a moderate level of generalization with clinical implications, metasyntheses may transform these findings into more highly abstracted and generalizable theoretical frameworks. These authors "*push their findings toward the nomothetic end of the idiographic-nomothetic continuum*" [46], an observation that raises two points that must be considered. The first is the question of context. Qualitative specialists certainly do not shy away from stressing the importance of context in their studies, or from arguing that the context of one study may not be applicable to others. It is true that, in a way, metasyntheses decontextualize concepts to attain greater generalizability [46]. But we can relate this act to the response of clinicians reading a qualitative paper: they will try to apply the concepts to their own situations [17]. Authors of metasyntheses are proposing their own interpretation of the concept and its generalizability.

The second aspect is the question of the level of evidence of the science produced by qualitative methods. This debate is perhaps the key point about qualitative

data in medical areas. Qualitative research assumes its subjectivity and takes account of each specific context. Speaking about reproducibility is simply not appropriate within the qualitative paradigm. The aim of a qualitative study is not to prove a truth in any context, but to describe one contextual situation that could improve our understanding of a complex phenomenon [81]. Qualitative research helps us to generate understanding and thus to develop theories that help to frame a given phenomenon. In this light, metasyntheses, which address the perspectives of more participants, engender broader understanding. Their results tend toward more universalism.

The scientific value of metasynthesis thus lies in its role as a summary of many studies and as the interpretation of a context, as well as in its ability to weight each result and to propose greater generalizability.

But how rigorous can metasyntheses be? Their rigor seems seriously impaired by the reduced effect of their context, by their consideration of published papers the research process of which they cannot provide a complete account, by their reliance on partial and selected transcripts of participants. After long work on quality assessment of primary studies in systematic reviews of qualitative studies, Tong et al (2014) proposed a guide to reading and assessing qualitative reviews, based on the following principles: credibility, dependability, transferability, and confirmability [86,29,76]. These principles are largely similar to those of Mays and Pope (2000), which discuss triangulation, reflexivity, clear exposition of the method of data collection and analysis, attention to negative cases, fair dealing, and respondent validation [81]. Our method meets all these of criteria of rigor.

First, triangulation is at the center of our metasynthesis approach. We included results involving participants and researchers from a broad range of professions and scientific backgrounds [46,67]. This triangulation is possible because we included numerous studies from diverse types of databases – medicine, nursing, psychology, and social science. A limitation of databases is that they include almost only scientific papers, while other types of reports (books, or research reports) are not included. This is certainly a limitation for those working on social science subjects, but not on medical research, which is almost only

reported as journal articles. To ensure adequate triangulation, it is important to vary the ways we collect data. Our decision to include various qualitative methods, from thematic or phenomenological studies to papers based on grounded theory, meets this need and facilitates more dialectic processes whereby ideas are challenged and modified [39,42,83]. Finally, the collaborative aspect of our work and the diverse backgrounds in our team (psychiatrists, child and adolescent psychiatrists, psychologists, or physicians) enhance our capacity of triangulation [43].

Secondly, because we consider the relationship between adolescents and their therapists in contexts such as suicidal behavior [56], we have worked to include perspectives of all stakeholders: the adolescents, the healthcare professionals, and the parents. Our intentionally broad screening of the literature enables us to include papers from a broad range of origins and cultures. Because, as mentioned above, the papers are based on a variety of background theories, the fair dealing principle is satisfied, and additional triangulation is promoted.

The constraints of scientific publication limit the ability of researchers to describe their method and backgrounds in detail. We nonetheless set out our medical and psychiatric perspective clearly in each publication, reporting our method as precisely as we can; whenever possible, we use online supplements to add more details. Lastly, this paper is the occasion to deal with our method and theoretical background [26].

Mays & Pope (2000) recommend paying attention to negative cases and discussing *"elements in the data that contradict, or seem to contradict, the emerging explanation of the phenomena under study"* [81]. Throughout the analysis process, we made an effort not to weight themes according to their frequency of occurrence, specifically to ensure the emergence of contradictory ideas. Nevertheless, a metasynthesis is a subjective proposition for understanding a phenomenon and may have as an inherent limitation difficulty in examining contradictions. Aiming to gain generalizability probably results in leaving aside some fragments of understanding [62].

A final aspect of the qualitative process is that it seeks validation from the participants. This aspect is obviously not achievable in metasynthesis, but

validation from the authors of the primary studies may be useful. We chose not to write to each individual author in advance to avoid delaying the publication process and because manuscripts change until final publication, but especially because they are all part of the scientific community. They surely keep in touch with new publications in their area of work. Furthermore, scientific publishers and networks have their own warning systems when papers are cited. We consider that the scientific community, first by peer review, then by comments and rights of reply, and finally, by citing or otherwise recommending (or not) our articles, has the capacity to validate or reject the results of our studies.

Qualitative research is an invaluable method for gaining new insights into mental disorders [6]. Its development in recent years requires that we improve methods for synthesizing their results. Researchers in psychology have already developed methods that emphasize theoretical comprehension [49], and those in nursing, methods that emphasize practical responses during care [104,105]. We think our method is appropriate to psychiatric research in its intermediate position that stresses both progress in the general comprehension of disorders and direct clinical implications.

The systematization of searching and inclusion is well adapted to a public of child and adolescent psychiatrists, familiar with the framework of meta-analyses. Moreover, qualitative scientific works are most often published in the format of scientific papers, that is, in one synthetic manuscript, listed in a scientific database (rather than as chapters in one or several books).

Our method is designed to offer an appropriate balance between three components: an objective framework, which includes the selection, inclusion, and appraisal of studies; a rigorously scientific approach to data analysis; and the necessary contribution of the researcher's subjectivity in the construction of the final work. The balance for a qualitative metasynthesis is, we think, very similar to the clinical approach to each patient. It necessitates a robust scientific background, a rigorous step-by-step – symptom by symptom – progression, and finally a part of *art* that depends on each clinician: the subjective part of therapy.

Finally, we think that metasyntheses enable insights that no other method can provide. Qualitative research sheds new light on scientific questions by

emphasizing the participants' subjective understanding and experience [6]. Metasynthesis proposes a third level of comprehension and interpretation that brings original insights. For example, in our study concerning suicidal behaviors [56], we emphasized an original point in the relationship: the violence of the message of suicidal behavior may interfere with the capacity for empathy of both family members and professionals. The original studies pointed out how difficult it can be for professionals and parents to understand and cope with suicide, even though none of the original studies constructed a theme or an equivalent category for this result. Our study's analysis went deeper and proposed original results.

Conclusions

We have developed a method for metasynthesis, based on thematic synthesis [17]. Our method is clear and rigorous and makes it possible to reach a high level of understanding and to identify immediate clinical implications. It has been tested in different psychiatric contexts in adolescence [55–58] and has improved both mental health care and our understanding of complex conditions and mental disorders.

Competing interest

The authors declare that they have no conflict of interest.

Authors' Contributions

Conceived and designed the experiments: JL ARL MO MRM. Conducted the literature review: JL, MO. Performed the experiments: JL MO ARL. Wrote the paper: JL (all the paper) ARL(analysis) MO(introduction and analysis) MRM (discussion). Final Approval : JL ARL MO MRM.

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DISCUSSION

A partir de deux métasynthèses publiées dans des revues internationales, ainsi qu'une revue exhaustive de la littérature méthodologique, notre travail permet de proposer un protocole méthodologique abouti permettant d'effectuer des synthèses qualitatives sur des thématiques qui concernent la psychiatrie de l'adolescent. Pourtant, comme le rappellent France et coll. (2016), les méthodes permettant la collecte et l'analyse des données qualitatives sont en perpétuelle évolution (France, Wells, Lang, & Williams, 2016). Alors que nous préparions notre troisième article, en 2016, plus de six cent métasynthèses ont été publiées, de même qu'un nombre important d'articles méthodologiques proposant parfois des avancées majeures.

Dans cette discussion, nous proposerons donc de présenter les dernières avancées méthodologiques concernant les métasynthèses. Nous avons choisi de présenter ces données en les inscrivant dans le contexte historique du développement des méthodes qualitatives en recherche médicale. Comme nous l'avons souligné en introduction, cette construction s'est faite d'abord en opposition aux méthodes de recherches classiques, et en particulier aux perspectives de *l'Evidence-Based Medicine* (médecine fondée sur les preuves, EBM). Le mouvement actuel va vers la mise en place de ponts, de protocoles utilisant quantitatif et qualitatif de manière complémentaire. Pour définir les limites de la recherche qualitative, il s'agissait ainsi d'abord de définir ce qu'elle *n'est pas*. Ce mouvement de déconstruction-reconstruction a permis de délimiter les objectifs et potentialités du qualitatif, de même que ses limites. Le retour vers le quantitatif s'est fait et continue de se faire dans une volonté de *singularisation par affiliation.* A chaque concept, notion, protocole quantitatif, les experts qualitativistes proposent un concept, une notion, un protocole adapté aux exigences épistémologiques qualitatives. C'est par exemple le cas des critères de crédibilité, fiabilité, transférabilité et de conformabilité proposés par Tong et coll. (Tong, Palmer, Craig, & Strippoli, 2014), qui viennent répondre point par point aux critères de validité, généralisabilité et reproductibilité issus du paradigme positiviste. La définition ne se fait plus par opposition mais plutôt par différenciation ou par contraste. Les allers-retours permanents entre affiliation et différentiation sont exemplaires de la démarche qualitative, inscrite dans des

allers-retours permanents entre les données et les constructions, entre descriptions et interprétations, entre théorie et pratique.

Le mouvement des métasynthèses suit la même dynamique, et la construction du CQIM group en est l'illustration. Nous proposerons donc tout d'abord de décrire la construction de ce groupe au sein de l'univers de la Collaboration Cochrane. Le mouvement initial d'opposition a aujourd'hui abouti, et on assiste à une affiliation aux concepts issus de la recherche quantitative dans toutes les étapes des métasynthèses. Dans notre deuxième partie, nous nous illustrerons tous les aspects de ce rapprochement par des exemples récents.

1. L'inscription des métasynthèses au sein de la Collaboration Cochrane : naissance du *Cochrane Qualitative and Implementation Methods Group*

La Cochrane Collaboration est une association internationale indépendante et à buts non lucratifs. Ses objectifs sont de proposer une information sur les soins disponibles à travers le monde et de promouvoir la recherche de preuve dans les études sur les soins et essais cliniques (Cochrane Collaboration, 2016). Les revues systématiques proposées par la Cochrane Collaboration sont considérées comme le gold-standard de la synthèse de preuves scientifiques quantitatives. Grace à de nombreux travaux sur les méthodes de revues, qui ont abouti à la construction de protocoles utilisés pour toutes les grandes revues de littérature à travers le monde. Les revues systématiques Cochrane sont aujourd'hui considérées comme impartiales et fiables (Noyes, 2010). La bibliothèque Cochrane possède la plus grande collection de revues systématiques sur les effets des interventions en santé.

Pourtant, dès les années 1990, des voix s'élèvent pour signifier les limites de la politique de la Cochrane Collaboration, surtout son utilisation exclusive d'essais contrôlés randomisés (RCT). En effet, une revue Cochrane apporte des preuves irréfutables de l'efficacité de tel ou tel soin mais ne nous apprend rien sur la manière dont les patients vivent ce soin, dans quelle mesure celui-ci répond à

leurs attentes, leurs objectifs, ou s'intègre dans leur vie quotidienne (Noyes, 2010). A la fin des années 1990, sous l'impulsion de Ian Chalmers - fondateur de la Cochrane Collaboration -, un groupe de réflexion méthodologique est organisé afin de réfléchir à l'intégration des données qualitatives dans les revues Cochrane (Hannes et al., 2013). Le groupe n'est formalisé qu'en 2006. Et malgré l'intervention du professeur Jenny Popay, en séance plénière, au Colloque Cochrane la même année, qui prône l'importance d'intégrer les résultats qualitatifs dans les revues systématiques, les instances académiques considèrent qu'il existe encore de nombreux obstacles à la réalisation de cet objectif (Hannes et al., 2013). Le chemin sera long jusqu'à la publication de la première synthèse qualitative dans la *Cochrane Database of Systematic Reviews* en 2013 (Glenton et al., 2013).

Dans les années 2000, le débat sur la 'méthode Cochrane' est très animé, et de nombreux auteurs se révoltent contre la position de la Collaboration d'exclure tout forme de preuve scientifique autre que les RCTs. Pour certains, le mouvement de l'EBM serait outrageusement *excluant*, dangereusement *normatif*, en résumé un bon exemple de *micro-fascisme* au sein de l'arène scientifique contemporaine (Holmes, Murray, Perron, & Rail, 2006). Il est vrai qu'à cette période, la Collaboration Cochrane propose une hiérarchie des preuves dans laquelle la recherche qualitative est au plus bas niveau (Noyes, 2010).

Durant cette première période, le développement des métasynthèses se réalise en opposition au quantitatif. La Meta-Ethnography, méthode princeps, repose sur des conceptions épistémologiques très éloignées de l'EBM. Les experts prônent l'échantillonnage raisonné des articles à inclure, surtout publiés dans les livres et la littérature *grise* (*Grey Literature*, documentation parallèle non publiée dans les revues ou les livres). Peu d'articles sont inclus et aucune évaluation de leur qualité n'est réalisée (Barbara L. Paterson, Thorne, & Dewis, 1998; Sandelowski, 1995). Les experts refusent l'idée de protocoles qui rendraient rigide une démarche de recherche qui doit rester flexible et s'adapter au contexte.

Cependant, la création du CQIM Group et son travail, qui aboutit à l'écriture d'un chapitre du *Cochrane Handbook of Systematic Reviews of Interventions* en 2008

(Noyes et al., 2011b) puis au *Supplementary guidance for inclusion of qualitative research in Cochrane systematic reviews of interventions* en 2011 (Noyes et al., 2016) - par manque de soutien au sein de la Collaboration Cochrane, la publication papier de ce guide n'a jamais aboutit (Hannes et al., 2013)-, sont une formidable preuve de la volonté des représentants du mouvement qualitatif à s'affilier au mouvement de l'EBM. Le CQIM group, comme d'autres acteurs important du développement des métasynthèses (Centre for Reviews and Dissemination, s. d.; EPPI-Centre, s. d.; ESRC, s. d.; Integrate HTA, s. d.; Joanna Briggs Institute, s. d.; NIHR, s. d.), s'appliquent à développer des protocoles pour définir précisément les étapes nécessaires à la construction d'une métasynthèse rigoureuse proposant des résultats fiables et de qualité. Alliant nécessaire rigueur et flexibilité indispensable au qualitatif. Ce mouvement de plus en plus actuel est celui d'un rapprochement, d'une *singularisation par affiliation*.

2. Vers une réconciliation des métasynthèses et de l'EBM ?

Durant les cinq dernières années, les *protocols*, *best-fit frameworks*, *how to* et autres *guidance on* au sujet des méthodes de métasynthèse n'ont fait que se multiplier sur le plan international. Les principaux auteurs sont issus des grands groupes de recherche épidémiologiques et groupes internationaux de réflexion méthodologiques : la Cochrane Collaboration, bien sûr, mais également le CRD (Centre for Reviews and Dissemination, s. d.), l'ESRC (ESRC, s. d.), l'EPPI (EPPI-Centre, s. d.), , Integrate-HTA (Integrate HTA, s. d.), le Joanna Briggs Institute (Joanna Briggs Institute, s. d.), ou encore le NIHR (NIHR, s. d.). Ces publications proposent le plus souvent une réflexion globale sur les métasynthèses, une liste des principales méthodes et des conseils pour construire son propre protocole adapté au contexte envisagé. Ils ne proposent pas de description pratique de la méthode, mais sont d'une aide précieuse pour choisir la méthode la plus adaptée et joignent les références des articles princeps de même que de nombreux exemples. Ces guidelines généralistes sont pourtant rapidement dépassés aux vues de multiples protocoles publiés concernant chaque étape de la

métasynthèse. Il peut s'agir de conseils pratiques guidant la démarche, ou de guides permettant l'évaluation de tout ou partie du travail. Ils s'intéressent à toutes les étapes de la synthèse, de protocoles en amont de la métasynthèse - notamment des guidelines de bonne publication de la littérature qualitative facilitant le travail de métasynthèse - jusqu'à l'aval, et la mise à jour des métasynthèses(France et al., 2016). Nous proposons de nous intéresser en détail à chaque étape:

- en amont des métasynthèse : le protocole COREQ (Tong, Sainsbury, & Craig, 2007), le SRQR statement (O'Brien, Harris, Beckman, Reed, & Cook, 2014) et l'approche Delphi explorent les potentialités pour la construction de guidelines de publication des études qualitatives (Hannes, Heyvaert, Slegers, Vandenbrande, & Van Nuland, 2015);
- pour la collecte des données : dans le choix de la méthode de recueil (Booth, 2016c), le choix des moteurs de recherche (Booth, 2016b) ou encore l'exposé des étapes de recueil dans les publication (Booth, 2006);
- durant l'analyse des données : pour choisir et adapter sa méthode aux données et aux éléments de contexte (Booth et al., 2016; Kastner, Antony, Soobiah, Straus, & Tricco, 2016), et inclure les articles proposant des thèses contradictoires dans la métasynthèse (Booth, Carroll, Ilott, Low, & Cooper, 2013; Finfgeld-Connett, 2016);
- dans l'exposé des métasynthèse dans les publications : protocoles généraux (Tong et al., 2012) ou spécifiques à une méthode de métasynthèse (France et al., 2015);
- pour l'évaluation des métasynthèses : le protocole GRADE-Cerqual (Lewin et al., 2015) ;
- Pour la mise à jour des métasynthèses publiées (France et al., 2016).

2.1. Bonnes pratiques dans l'exposé des publications qualitatives

Pour chaque type de recherche il existe un guide, le plus souvent sous la forme de checklist, de bonnes pratiques concernant l'exposé de la recherche dans des publications scientifiques : CONSORT pour les RCTs, STARD pour les tests diagnostics, QUOROM pour les méta-analyses de RCTs, STROBE pour les études observationnelles, CARE pour les case reports, PRISMA pour les revues systématiques ou encore MOOSE pour les méta-analyses d'études observationnelles. L'avantage de l'utilisation de ces protocoles est double : ils augmentent le degré de consistance de la littérature scientifique, en proposant aux auteurs des instructions claires sur les informations indispensables à la publication de l'exposé de leur recherche ; ils facilitent l'évaluation de la qualité méthodologique en imposant de détailler les choix méthodologique de chaque recherche (Hannes et al., 2015). Le site internet EQUATOR network recense ainsi plus de 320 protocoles existant pour les différents types de recherches médicales (EQUATOR Network, 2016). Pourtant, jusqu'à la publication proposée par l'équipe australienne de Tong et coll. en 2007, aucun protocole unifié ne proposait de critères de bonne pratique pour l'exposé des recherches qualitatives qui puisse s'appliquer à tout type de méthode qualitative. Chaque méthode était accompagnée de sa grille facilitant son écriture, incompatible avec les autres méthodes (Knafl & Howard, 1984; Tong et al., 2007). La diversité des méthodes, le besoin de flexibilité et d'adaptabilité au contexte, les dissensions épistémologiques, étaient autant d'arguments de résistance à la construction de protocoles communs à toute recherche qualitative médicale. La croissance importante du nombre de publications qualitatives a pourtant rendu ces guidelines indispensables : l'exposé inadéquat de recherches qualitatives de mauvaises qualité nuit à l'ensemble de la recherche qualitative et de la recherche en général (Tong et al., 2007). L'exigence de plus de transparence des exposés est devenue prégnante.

Le Consolidated criteria for reporting qualitative research (COREQ) répond à cette exigence. Construit à partir d'une analyse de littérature des checklists existants, le COREQ est une checklist de 32 items spécialement adaptée aux

recherches utilisant des entretiens et focus groups. Les items sont regroupés en trois domaines :

- Domaine de l'équipe de recherche et la réflexivité : qui est l'interviewer, quel est son background...
- Domaine du design de l'étude : quelle est la méthode, la théorie, le type d'échantillonnage, les participants...
- Domaine de l'analyse et des résultats : description du codage, utilisation de logiciels, consistance des données, clarté de l'exposé...

Le COREQ, dès sa publication, a été vivement critiqué par de nombreuses voix du milieu qualitatif : trop rigide, trop général, peu adapté aux spécificités de chaque recherche. Il est pourtant de plus en plus utilisé et recommandé par de nombreuses revues internationales.

Une équipe américaine a proposé une alternative au COREQ, publiée en 2014 : le Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014). Le SRQR comporte 21 items regroupés en en 6 domaines :

- Titre et abstract
- Introduction : formulation de la question de recherche et des objectifs
- Méthodes : paradigme de recherche, reflexivité, contexte, échantillonnage, éthique, recueil des données, outils de recueil, analyse, rigueur scientifique
- Résultats : synthèse et interprétation, mise en lien avec les données de la littérature
- Discussion : intégration avec les précédents travaux, implications, transférabilité et limites
- Autres : conflits d'intérêt et sources de financement

Selon les auteurs, le SRQR aurait l'avantage de préserver la flexibilité indispensable pour s'adapter aux multiples paradigmes, approches et méthodes.

Ces deux protocoles sont construits à partir de revues de littératures. Et du fait de l'absence de consensus dans le milieu des experts qualitatifs, l'équipe belge de

Hannes et coll. (2015) s'est décidée à interroger un groupe d'experts à l'aide d'une *argument Delphi approach* afin de mettre en évidence les positions communes et ouvrir le travail vers la constitution de protocoles consensuels (Hannes et al., 2015). Les experts interrogés s'accordent à dire que des protocoles sont nécessaires afin d'améliorer la transparence dans les exposés. Cependant, peu d'entre eux sont favorable à la constitution d'une liste de critères extensifs : des recommandations essentielles minimales et un cadre général sont les deux propositions plébiscitées par les participants. Les principaux arguments sont principalement l'importance de laisser un grand degré de flexibilité aux chercheurs, et à l'émergence de nouvelles méthodes. La recherche qualitative médicale demeure une discipline jeune, et trop de contraintes risqueraient de limiter sa créativité. Cependant les protocoles présentés ci-avant (COREQ et SRQR) répondent partiellement à cette attente : ils sont génériques et applicables à toutes les méthodes qualitatives. Cependant, ils manquent certains éléments souvent centraux des recherches qualitatives - par exemple l'exposé des réactions des participants aux résultats de l'étude, la capacité d'une étude à donner une place centrale aux participants, les liens avec la littérature existante sur la thématique, les motivations du choix de l'étude, de son design, de sa méthode... - (Hannes et al., 2015, p. 14). Ils nécessitent d'être adaptés à la lumière des avis d'experts.

2.2. 'Searching for qualitative research' : bonnes pratiques en matière de revue de littérature

C'est une des étapes essentielles de toute revue de littérature. De même qu'un chercheur quantitatif étudie longuement les modalités d'inclusion de ses participants, qu'un chercheur qualitatif optimise l'inclusion de participants les plus informants possible, ceci afin de maximiser la richesse des données à analyser, un auteur de revue de littérature doit se pencher sur les modalités de recueil de ses données : les articles inclus.

Nous l'avons vu dans notre troisième article, il existe un continuum entre échantillonnage raisonné et revue systématique au sein duquel le débat fait rage entre les experts méthodologistes. L'échantillonnage n'est pourtant pas le seul

élément à prendre en compte dans le recueil des données. Booth et coll. (2016) a récemment publié une revue méthodologique structurée des étapes de recherche et d'inclusion de la littérature d'une métasynthèse (Booth, 2016c). Il y décrit 5 domaines à prendre en compte :

- L'échantillonnage : son type, combien d'études doit-on inclure, quand interrompre sa recherche, les difficultés rencontrées
- Les sources : les bases de données, la littérature *grise*, les livres et chapitres de livres, les thèses et manuscrits
- La procédure de recherche : structure des questions pour interroger les bases de données, inclusions, stratégies et utilisation des filtres de recherche
- Les stratégies complémentaires : vérification des citations, des références, contact d'experts
- Les protocoles de bonnes pratiques d'exposé des méthodes de recherche dans les publications

Les tensions autour de la technique d'échantillonnage sont constantes au sein du mouvement qualitatif. Le gold standard proposé par Noblit et Hare opte pour un échantillonnage raisonné à une période où la plupart des études qualitatives sont publiées de manière extensive dans des livres (Noblit & Hare, 1988). Aujourd'hui, les études qualitatives sont d'avantage publiées dans les revues médicales de façon synthétique, ce qui va en faveur d'un échantillonnage systématique. Les réflexions théoriques actuelles proposent l'idée d'un échantillonnage étendu (*comprehensive*) ou exhaustif (*exhaustive*), abandonnant ainsi le mythe de la complétude absolue de l'échantillon. Sans répondre à la question du nombre d'études, ni du moment propice pour terminer sa recherche, Booth et coll. proposent d'adapter la technique d'échantillonnage au type de métasynthèse : aux méthodes numériques convient souvent mieux un échantillonnage systématique, aux méthodes interprétatives, un échantillonnage raisonné, enfin, aux méthodes narratives, un échantillonnage exhaustif.

Les sources classiques des méta-analyses quantitatives et de beaucoup de métasynthèses qualitatives scientifiques sont les bases de données scientifiques.

Parmi elles, CINAHL et MEDLINE sont les plus adaptées pour retrouver des études qualitatives (Booth, 2016b). Les auteurs rappellent l'intérêt de compléter les recherches avec des bases de données de sciences sociales (SSCI). Bien qu'une proportion importante de recherches qualitatives ne sont encore pas publiées (Toews et al., 2016), l'utilisation de la littérature grise n'est plus aussi vraie qu'auparavant. Enfin, les livres et thèses sont sujets à discorde : l'extensivité de ce type de documents présente un intérêt en termes de richesse mais limite la possibilité d'inclure d'avantages d'études. Le conseil est ici d'inclure, lorsqu'ils existent, les articles dérivés des thèses et livres.

Plusieurs outils ont été proposés pour adapter le PICO, outil de systématisation de l'iterrogation des bases de données issu du monde quantitatif (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014) : 3WH, BeHEMoTh, CIMO, ECLIPSe, PEICO(S), PICo, PICOC, PICOS, SPICE, SPIDER (**TABLEAU 3**). Les protocoles sont plus ou moins sensibles ou spécifiques, les auteurs rappellent que le PICO est plus adapté lorsque l'objectif est une plus grande sensibilité tandis que le SPIDER sera préféré lorsque l'objectif est la plus grande spécificité. La balance sera choisie en fonction du type de métasynthèse.

Tableau 3 – Présentation des différentes approches qualitatives structurées pour interroger les bases de données (adapté de (Booth, 2016b)**)**

Nom	Composition
3WH	What (sujet), Who (participant), When (Période), How (méthode)
BeHEMoTh	Behaviour, Health context, Exclusions, Models of Theories
CIMO	Context, Intervention, Mechanisms, Outcomes
ECLIPSe	Expectations, Client Group, Location, Impact, Professionals involved, Service
PEICO(S)	Person, Environment, Intervention, Comparison, Outcomes, (Stakeholders)
PICO	Population, Intervention, Comparaison, Outcomes
PICo	Population, Phenomenon of interset, Context
PICOC	Population, Intervention, Comparaison, Outcomes, Context
PICOS	Population, Intervention, Comparaison, Outcomes, Study type
SPICE	Setting, Perspective, intervention/phenomenon of interest, Comparison, Evaluation
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research Type

L'utilisation des filtres proposés par les bases de données doit toujours rester spécifique à chaque base de données. Certains filtres seraient ainsi plus sensibles, d'autres plus spécifiques. Par exemple, pour Medline, *interview*[Title/Abstract] OR psychology[Subheading:noexp]* serait très sensible, tandis que *Qualitative[Title/Abstract] OR Themes[Title/Abstract]* serait très spécifique.

Les auteurs suggèrent d'inclure des méthodes complémentaires de recherche, en s'appuyant sur les références, en interrogeant manuellement les revues, ou encore en prenant contact avec des experts de la question. Ces méthodes sont souvent lourdes techniquement et leur utilité semble accessoire. Les auteurs proposent toutefois un protocole pour ces recherche, le CLUSTER (Booth, Harris, et al., 2013).

Enfin, deux protocoles proposent une évaluation des bonnes pratiques concernant la revue de littérature d'une métasynthèse. Le protocole ENTREQ (voir plus loin) possède plusieurs items en rapport avec la revue : approche de la recherche (item 3), critères d'inclusion (item 4), sources de données (item 5) et stratégie de recherche électronique (item 6) (Tong et al., 2012). Ces items sont largement inspirés du protocole STARLITE, acronyme de Standards for Reporting Literature Search, spécifiquement dédié aux stratégies de revues de littérature (Booth, 2006) (**TABLEAU 4**).

Tableau 4 – Eléments du protocole STARLITE

S	Sampling strategy	systématique, exhaustive, raisonnée
T	Type of Studies	Complètement ou partiellement décrit
A	Approaches	Autres que l'utilisation de bases de données
R	Range of years	Complètement ou partiellement décrit
L	Limits	Limites fonctionnelles (ex : langue)
I	Inclusion and exclusions	Limites conceptuelles
T	Term used	Complet ou partiel
E	Electronic sources	Bases de données

2.3. Bonnes pratiques dans le choix de la méthode d'analyse

L'analyse des données des articles inclus est l'étape centrale de la métasynthèse. Elle est à la fois éminemment subjective et considérablement théorisée. C'est dans cette étape que se différencient véritablement les méthodes de métasynthèses. L'objectif de chaque type de méthode va dicter le déroulement de l'analyse. Mais elle est également très opérateur dépendant, et de fait très difficile à protocoliser.

Jusqu'à la fin des années 2000, peu de réflexions étaient portées au choix de la méthode. Les auteurs utilisaient le plus souvent la méthode qui leur était familière, et qui de fait était le plus souvent adaptée aux objectifs qu'ils visaient. L'amplification du mouvement des métasynthèses a entraîné l'utilisation de ces méthodes par des néophytes, ainsi que l'hyperspécialisation de certains chercheurs dans le domaine des métasynthèses. Ces derniers se sont intéressés à différentes méthodes et à leurs indications. Leurs travaux aboutissent à la publication des premiers arbres décisionnels, par exemple dans le Cochrane Handbook for Systematic Reviews of Interventions (Noyes, Popay, Pearson, Hannes, & Booth, 2011a). Il est précisé que le choix doit se faire sur différents critères incluant :

- le type et le sujet de la revue et de la question posée dans la revue
- le pool de résultats déjà publiés sur le sujet
- le degré d'expertise de l'équipe
- les ressources existantes

Le Supplemental Handbook Guidance du CQIM précise ces critères, en proposant un choix entre quatre objectifs de la revue : les *informing reviews,* les *enhancing reviews*, les *extending reviews*, et les *supplementing reviews*. Des grands types de méthode – interprétatives, descriptives, agrégatives – et des exemples concrets sont proposés pour chaque objectif (Noyes et al., 2016).

L'équipe INTEGRATE-HTA (Union Européenne) menée par le Professeur Andrew Booth publie en 2016 un guide complet d'aide au choix de la méthode de

métasynthèse pour l'évaluation des technologies de soins (Health Technology Assessment) (Booth, 2016a). 19 méthodes sont classées sur plusieurs critères :

- le type d'articles inclus : qualitatifs et quantitatifs
- l'épistémologie : idéalisme ou réalisme, nécessité ou pas d'une compatibilité entre l'épistémologie de la métasynthèse et des études inclues
- la durée nécessaire à l'accomplissement de la revue
- le type de données : échantillonnage, importance de la recherche de données
- l'expertise nécessaire : dans la méthode de revue et dans le domaine exploré
- le public attendu de la revue : universitaires, cliniciens, décideurs de politiques de santé…
- le type de données : thick et thin data (importance donnée au contexte) et rich et poor data (importance donnée à la conceptualisation théorique)
- la possibilité d'utiliser un protocole d'exposé (type ENTREQ)

L'équipe de Kastner et coll. (2016) va encore plus loin en proposant un algorithme destiné à optimiser le choix de la méthode de métasynthèse (Kastner et al., 2016). L'algorithme considère d'abord l'objectif de la revue, puis le type d'articles inclus, et enfin les productions attendues. Les cinq types d'objectifs sont :

- pour générer ou affiner une théorie ou une hypothèse théorique
- pour explorer l'expérience des participants, leurs perceptions, leurs préférences, leurs croyances et valeurs
- pour identifier des thématiques nécessitant d'avantage de recherche
- pour explorer les aspects méthodologiques d'un sujet
- Pour développer des modèles, des guidelines ou des échelles de mesure

Vingt méthodes sont réparties dans ces différents objectifs.

Enfin, en ce qui concerne l'analyse des données, une spécificité des synthèses qualitatives est la nécessité de prendre en compte les variations, les cas déviants, les dissonances, les ambiguïtés (Finfgeld-Connett, 2016). Ces dissonances, si importantes en qualitatif car c'est souvent dans la divergence qu'est généré le maximum de théorie, sont fragilisées par le concept même de la synthèse qui tend à résumé, synthétiser, unifier. Un article de 2013 propose une checklist à valider pour limiter le risque d'uniformisation des résultats :

- l'équipe de recherche : travail en équipe, pluridisciplinarité, exposé de la réflexivité, légitimation de la culture du questionnement au sein de l'équipe.
- La méthode de revue : multiplier la durée et la fréquence d'exposition aux données, utiliser différentes méthodes d'analyse, analyses par sous-groupes.
- La théorie : possibilité de tester différentes théories explicatives ou cadres théoriques appliqués aux résultats.
- La présentation des résultats : proposer un tableau de thèmes et leur apparition dans les articles, proposer une validation des résultats par les auteurs ou les participants.

2.4. Bonnes pratiques dans l'exposé des résultats

La multiplication des métasynthèses dans de nombreux domaines de santé a incité les éditeurs à demander aux auteurs de joindre à leurs revues des protocoles de bonnes pratiques d'exposé des résultats (reporting protocols) tels que le protocole PRISMA (D. Moher, Liberati, Tetzlaff, Altman, & for the PRISMA Group, 2009). Ce protocole n'étant pas adapté aux métasynthèses, plusieurs équipes ont travaillé sur l'élaboration de protocoles adaptés. Trois principaux protocoles existent aujourd'hui : ENTREQ (Tong et al., 2012), eMERGe (France et al., 2015), et RAMESES (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013). Les deux derniers étant destinés au méta-narrative reviews (RAMESES) et aux méta-ethnography (eMERGe), nous ne les détailleront pas ici.

Le protocole ENTREQ a été développé par la même équipe que le protocole COREQ que nous avons détaillé plus tôt. Il est adapté aux principales méthodes de métasynthèses utilisées en recherche médicale. Il est perfectible, puisqu'il n'a pas été conçu à l'aide d'une approche Delphi comme recommandé dans la littérature (David Moher, Schulz, Simera, & Altman, 2010). Il est toutefois intéressant et a été adopté par la plupart des grandes revues. Il se compose de 21 items à référer au manuscrit comme le PRISMA statement (**TABLEAU 5**).

Tableau 5 – Description des items du protocole ENTREQ

Item	Description
1	Objectifs
2	Méthode de synthèse
3	Méthode de recherche des articles
4	Critères d'inclusion
5	Sources de données
6	Stratégies de recherche numérique
7	Screening des études
8	Résultat de la sélection des études
9	Justification de l'évaluation de la qualité des études
10	Items d'évaluation de la qualité des études
11	Procédure d'évaluation de la qualité des études
12	Résultat de l'évaluation de la qualité des études
13	Type de données extraites
14	Logiciel utilisé pour l'aide à l'analyse
15	Nombre de reviewers
16	Méthode de codage
17	Méthode de comparaison des études
18	Méthode de construction thématique
19	Publication de verbatim
20	Qualité de la synthèse

2.5. Bonnes pratiques dans l'évaluation de la qualité des métasynthèses

Lorsque les données d'une revue systématiques sont utilisées par les décideurs de politiques de santé, il est nécessaire de classer la qualité des résultats présents dans chaque revue. Les tentatives de validation par les participants sont aujourd'hui peu concluants et difficiles à mettre en pratique (Bayliss et al., 2016). Dans un tout autre registre quantitatif, le GRADE Working group (Grading of Recommandations Assessment, Development and Evaluation) propose depuis 2004 un guide pour évaluer clairement et de manière transparente le niveau de confiance à apporter à chaque résultat (Guyatt et al., 2011). L'équivalent qualitatif du GRADE vient d'être publié par un groupe de travail issu du CQIM (Lewin et al., 2015). L'objectif du GRADE-CERQual est d'évaluer de manière transparente le niveau de confiance à donner aux résultats issus d'une métasynthèse. Les items évalués sont les limitations méthodologiques, la pertinence, la cohérence et l'adéquation des résultats.

Les limitations méthodologiques sont constituées des problèmes relevés dans le design ou le déroulement des études inclues dans la métasynthèse. La pertinence est l'adéquation entre le contexte des études inclues et celui de la métasynthèse. La cohérence est la qualité de lien entre les données du terrain, les interprétations des auteurs et celles des reviewers. Enfin, l'adéquation des résultats est le degré de richesse et la quantité de données justifiant les résultats.

L'évaluation finale propose un classement en quatre niveaux : Confiance élevée, modérée, basse, très basse. Ces niveaux correspondent aux niveaux de qualité proposés par le GRADE, et rappellent étrangement les niveaux de preuve de l'EBM.

2.6. Bonnes pratiques dans la mise à jour des métasynthèses

Le fait que la question puisse être abordée dans la littérature montre le développement des métasynthèses ces dernières années. La mise à jour d'une revue systématique est protocolisée par la Cochrane Collaboration, elle doit

s'effectuer tous les deux ans pour maintenir l'assurance de la pertinence des résultats (Higgins & Green, 2011). Une équipe anglaise s'est penchée sur la question des mises à jour des métasynthèses (France et al., 2016). Elle propose un arbre décisionnel pour répondre à cette question. Les principaux éléments sont les objectifs initiaux de la métasynthèse, sa qualité, la pertinence de sa question et de sa méthode, et l'existence de nouvelles données ou d'avancées méthodologiques. En fonction des réponses à ces différentes questions, la procédure peut être de trois ordres :

- addition des articles et révision de la métasynthèse existante
- nouvelle métasynthèse sur les nouvelles données comparée secondairement aux résultats initiaux
- nouvelle métasynthèse à partir des anciennes et nouvelles données sans report à la précédente métasynthèse

2.7. Le futur des métasynthèses

Quel futur pour les métasynthèses ? Il est très probable que leur nombre continue de progresser. En guise d'exemple, la base de données de la Cochrane Collaboration comptabilisait le 5 aout 2016 721 entrées qui concernent la santé mentale. Des difficultés seront à dépasser, notamment dans le design des études, et la question d'inclure ou pas les études qualitatives et quantitatives dans un même travail (Finfgeld-Connett, 2016). Des enjeux méthodologiques également : selon certains auteurs, encore trop de travaux peu rigoureux sur le plan méthodologique sont publiés. L'importance à donner aux dissonances est également une question méthodologique importante (Finfgeld-Connett, 2016). Mais l'enjeu le plus imminent est celui de l'application des résultats à la pratique clinique. Les efforts de rapprochement de la métasynthèse aux référents quantitatifs permettent d'envisager d'avantage la participation des synthèses qualitatives à la production de preuves scientifiques. Pourtant, les développeurs de guidelines donnent encore trop peu de place aux résultats qualitatifs (Finfgeld-Connett, 2016). Les métasynthèses ont pourtant le potentiel non seulement de vérifier, de clarifier, d'élaborer, d'approfondir les protocoles de soins, mais aussi de les expliquer, de les préciser, de les réfuter, et d'élaborer leur

cadre (Sandelowski, 2004). La médecine fondée sur les preuves est une science complexe, qui implique de nombreux éléments intriqués : la qualité et la disponibilité des preuves, des cliniciens compétents et informés, des patients disposés à contribuer à la génération des données, ou des infrastructures (Noyes, 2010). On ne peut pas proposer de hiérarchie de preuves entre quantitatif et qualitatif, car leur valeur dépend profondément du contexte : « *le débat n'est pas dans la hiérarchie des preuves, et les mécanismes pour les classer et les utiliser pour déterminer l'efficacité des interventions, il est bien autour de la valeur à donner à différents types de preuves de bonnes qualité dans des contextes spécifiques* » (Noyes, 2010, p. 529). Il est nécessaire de proposer différents niveaux de preuves pour des types de questions différents : « *la domination et l'application d'un seul classement à tous les contextes est inefficace et ne permet pas de bâtir une médecine fondée sur des preuves solides.* » (Noyes, 2010, p. 533). Comme l'ont montré Naudet et coll. (2014), la preuve apportée par les RCTs n'est pas absolue et elle doit être complétée par d'autres types d'études, notamment les études observationnelles (Naudet, Maria, & Falissard, 2011). Les histoires que les RCTs racontent ne disent rien « *de l'histoire individuelle du patient que le clinicien a en face de lui ».* Elles ignorent *« un pan entier de thérapeutique qui joue un rôle central : le soin qui repose sur ce qu'on pourrait appeler l'irrationalité du patient, qui n'a aucune place dans les histoires proposées par l'EBM* » (Naudet & Falissard, 2014, p. 2).

CONCLUSION

Notre travail a débuté par une 'dissection quasi anatomique' du paradigme qualitatif et des conceptions théoriques sous-jacentes aux métasynthèses. A partir de ces éléments nous avons construit une méthode actuelle, rigoureuse, fiable et adaptée à notre discipline. Nous avons replacé notre méthode dans le mouvement de création du savoir médical fondé sur les preuves. La métasynthèse nous apparait incontournable dans l'élaboration du savoir psychiatrique. Elle vient compléter l'arsenal méthodologique, d'une richesse unique, qui va des protocoles neurobiologiques aux études inspirées des sciences humaines.

La démarche qualitative est à la fois proche et distincte de méthodes classiques en recherche psychiatrique telle que l'analyse de cas. Proche par l'importance donnée à la subjectivité du chercheur – subjectivité qui, nous l'avons vue, ne recouvre pas tout à fait les mêmes concepts en psychanalyse et en recherche qualitative. Proche par l'objectif de quête de sens : compréhension d'un phénomène en qualitatif, signification du symptôme et du conflit psychique en psychanalyse (Gilbert, 2007). Proche par la position du sujet : participant expert en recherche qualitative, analysant qui possède le savoir en psychanalyse. Proche enfin par le caractère inductif de la méthode. Toutefois, c'est ici qu'on peut vraiment séparer recherche qualitative et recherche psychanalytique. La première propose une méthode la plus inductive possible : selon Glaser et Strauss, la démarche initiale consiste à mettre de côté tous les éléments théoriques pour laisser les hypothèses émerger du terrain de recherche (Glaser & Strauss, 1967). Le cadre théorique se limite à l'organisation du cheminement de l'analyse du discours. La démarche est phénoménologique, le chercheur s'attardera sur telle ou telle unité de sens, il pourra s'agir d'un mot, d'une phrase, d'une élision ou d'un élément syntaxique. La théorie arrive après, elle est **le fruit de l'analyse**. En psychanalyse, on ne pose pas d'hypothèse a priori sur le fonctionnement psychique du sujet. En revanche, la conception de l'étude et l'analyse des données sont guidées par les concepts théoriques psychanalytiques. L'attention sera portée sur tout élément permettant d'accéder à une compréhension des conflits inconscients du sujet. Ce faisant, d'autres éléments appartenant à la réalité psychique du sujet ne seront pas pris en compte. La théorie est donc à la fois **à l'origine et à l'aboutissement de**

l'analyse. On se place dans un corpus théorique, position à partir de laquelle on analyse une situation. L'aboutissement de l'analyse est une proposition explicative qui permet de générer de la théorie. La démarche psychanalytique est donc déductivo-inductivo-déductive. Elle est proche de la démarche qualitative en ce sens qu'elle ne cherche pas à prouver dans la répétition, mais plutôt comprendre dans la singularité. Mais les deux sont bien distinctes dans leur manière d'aborder les données.

Nos sociétés sont en perpétuelle évolution. La tension entre collectif et individuel est une clé de compréhension de cette évolution, et l'individualisme n'a jamais été autant au centre du fonctionnement social qu'aujourd'hui. La progression des pathologies dites 'du narcissisme' de même que de nombreux troubles anxieux de l'adolescence seraient liés à cette évolution sociétale. Dans un tout autre domaine, le classement de l'information à l'ère du tout numérique et des big data est exemplaire de cette prééminence de l'individuel. En ce qui concerne la hiérarchisation des informations numériques, ces dernières années ont été marquées par l'affaiblissement des arguments de *popularité* et *d'autorité* et l'hégémonie de l'argument de *réputation* (Cardon, 2015). Les systèmes de mesure *d'audience*, de *popularité*, les *avis experts* et le *classement méritocratique* et démocratique de l'information numérique initiée par Médiamétrie puis Google ou Wikipédia sont ainsi détrônés par *l'e-réputation*, un réputation construite à grands renforts de *tweets*, de *like*, de *notes* et *d'avis*. Chacun a pu faire l'expérience de se connecter sur des sites tels que *Trip Advisor*© avant de réserver l'hôtel de ses vacances afin de vérifier les conseils des internautes pour 'ne surtout pas choisir la chambre 124 très bruyante puisqu'à côté du local de climatisation…' Les sites de réservation touristiques proposent d'ailleurs la plupart, en lieu et place des habituelles recommandations de guides touristiques, un module affichant les avis des internautes. Les opinions individuelles font ainsi jeu égal avec les arguments d'autorité et de popularité, et participent à la construction de la connaissance.

La relation clinique a également beaucoup évolué et la place du patient dans la prise de décision est devenue centrale (Bardes, 2012). Le tournant de la

médecine dite *centrée sur le patient* s'est accompagnée d'éducation et de responsabilisation (Saout et al., 2008). Le patient est de plus en plus l'expert de sa maladie et le décideur de ses soins. Le soin est individualisé, adapté à chaque patient. Il devient alors important que les représentations et opinions des patients participent à la construction du savoir.

Il est fort probable que cette évolution de la société ait également participé l'émergence et le développement des méthodes qualitatives en recherche médicale, puisque celles-ci utilisent comme données les représentations individuelles contextualisées. En recherche comme en informatique, une place de plus en plus grande est accordée à l'opinion individuelle.

Il apparait cependant risqué d'imaginer un passage du tout quanti au tout quali. De même que nous aurons toujours besoin des avis d'experts pour choisir nos destinations de vacances, nous avons besoin de preuves statistiques pour construire les protocoles de soins destinés au plus grand nombre. Des exemples préoccupants de l'actualité viennent illustrer ce risque ; l'évolution de la politique vaccinale francaise en est un. Les discussions autour d'une possible disparition de l'obligation vaccinale fait suite aux inquiétudes vis-à-vis de potentiels effets indésirables largement diffusées sur internet et facilement déconstructibles scientifiquement. Il ne s'agit pas ici de proposer un débat sur la nécessité ou pas d'une obligation vaccinale –ce débat appartient à la politique ; la science a montré qu'une couverture minimale de 95% de vaccinés est nécessaire pour protéger toute la population, mais elle ne dit rien quant aux décisions nécessaire pour parvenir à cette couverture vaccinale–, mais de souligner le danger d'une totipotence de l'opinion individuelle en matière de santé publique.

Le défi de demain est donc de trouver un équilibre entre individualisme et uniformisme. Dans cet équilibre la recherche qualitative et exploratoire doit permettre d'apporter les éléments de singularité permettant de générer des hypothèses théoriques ; la recherche quantitative statistique, d'asseoir ces théories et d'apporter des preuves à l'échelle des populations.

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