Rapport final de recherche

Emploi, Parcours de soins et Autonomie des JEUnes adultes avec Paralysie cérébrale : données européennes

PAJEUP

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NOTE D'INSTRUCTIONS AUX AUTEURS

Le rapport final vise à **présenter les résultats de recherche** soutenue au titre d'un appel à projets de l'IReSP. Complété par **l'annexe budgétaire finale**, ce dossier permet de rendre compte de l'ensemble du travail mené par les personnes impliquées dans ce projet.

Il est demandé au **coordonnateur scientifique du projet**, en incluant les éléments des éventuelles équipes partenaires, d'établir un rapport sur le modèle décrit ci-après et de le communiquer à l'IReSP à la **date indiquée par la convention**.

> ⚠ Pour les **réseaux et communautés mixtes de recherche,** un modèle de rapport final est en cours de construction. Dans l'attente de sa mise en ligne, vous êtes invités à utiliser ce modèle, en l'adaptant selon les spécificités de ces modalités.

1. Le contenu du rapport

Le dossier de rapport final de recherche comprend **deux parties** : une partie scientifique et une partie sur la valorisation.

1.1. Une partie scientifique

Cette partie permettra d'apprécier le travail scientifique réalisé par les équipes durant toute la durée de la recherche et de prendre connaissance de ses résultats. Elle pourra faire l'objet d'une relecture par un expert extérieur (qui devra signer un engagement de confidentialité).

Elle se décline en **trois sous-sections distinctes qui visent des objectifs et des lecteurs différents et qui ont vocation à être consultées indépendamment les unes des autres** : un résumé en français et en anglais, une synthèse longue en français et le rapport scientifique complet (**uniquement pour les projets financés dans le cadre du programme Autonomie soutenu par la Caisse nationale de solidarité pour l'autonomie, CNSA**, et rédigé en français).

- **<u>Un résumé en français et en anglais</u>**

Dans ce résumé, vous communiquerez **les principaux éléments de la recherche**. Il doit être formulé de manière **simple et claire,** de sorte à **être compréhensible par un public initié mais non spécialiste du sujet.**

Le résumé sera **publié en l'état sur le site de l'IReSP** et sur tout autre support de diffusion de l'IReSP et du ou des financeur(s) afin de donner de la visibilité au projet et ses résultats.

Il doit présenter :

- le **contexte** et les **objectifs** du projet ;
- la **méthodologie** utilisée (très brièvement) ;
- les principaux **résultats** obtenus ;
- les apports ou **impacts potentiels** de ces résultats.

Deux versions doivent être rédigées, l'une en **français** et l'autre **anglais.**

Le format de chaque résumé est de **1 page en format A4.**

- **Une synthèse longue en français**

Cette synthèse permet de rendre compte des résultats de projet au(x) financeur(s) et autres membres du GIS-IReSP. Un effort particulier est attendu concernant la rédaction de ce document car c'est celui qui sera mobilisé de manière privilégiée au sein des institutions publiques afin d'éclairer leurs décisions. Il doit **présenter la méthodologie employée et les résultats obtenus afin de mettre en évidence leurs apports pour la communauté de la recherche et/ou pour la décision publique.**

La synthèse pourra être publiée **sur le site de l'IReSP et/ou sur les sites internet des financeurs** et sur tout autre support de diffusion de l'IReSP et du.es financeur.s.

Cette synthèse longue doit comporter entre **10 et 15 pages**.

Elle présente :

- **les messages clés du projet** dans un encart (ses résultats principaux, l'originalité du projet, ou encore ses apports pour la santé publique et/ou les politiques de l'autonomie) ;
- le **contexte** et les **objectifs** du projet ;
- la **méthodologie** utilisée (deux pages maximum) ;
- les principaux **résultats** obtenus ;
- les **apports** potentiels de ces résultats pour la communauté de recherche ;
- la manière dont ces résultats peuvent éventuellement **alimenter les réflexions et actions** de **décideurs**, **acteurs nationaux ou locaux**, ainsi que des professionnels des secteurs sanitaire, médico-social, social ou autres acteur, le cas échéant ;
- Dans le cadre d'une **recherche interventionnelle** : les **conditions de transférabilité** ou de mise à l'échelle et les points de vigilance (⚠ si applicable) ;
- les **perspectives de recherches** ;
- les **15 principales références bibliographiques citées** en mettant en évidence, en caractères gras, les publications issues du projet (les autres publications issues du projet feront l'objet d'un recensement exhaustif dans la partie « Valorisation des résultats de la recherche »).

Si besoin, il est possible de réorganiser ce plan.

> ⚠ Pour les **projets d'amorçage, projets pilote, contrats de définition et pour la mise en place de projets européens,** préciser : 1. les **conditions de faisabilité** du projet de recherche que vous envisagez de mener à partir de ce premier travail et 2. les principaux points sur lesquels il convient d'être **vigilant** concernant l'étude à venir, la **méthodologie**, les **partenariats**, les **coûts** ou encore le **calendrier**.

- **Rapport scientifique complet en français**

> ⚠La rédaction du rapport scientifique complet n'est **requise que pour les projets financés** par la CNSA (hors **projets d'amorçage**, **contrat de définition, communautés mixtes des recherches** et les soutiens accordés pour la **mise en place de projets européens).**

Le rapport scientifique complet doit permettre de présenter de manière approfondie la **démarche scientifique** du projet et ses **résultats**. Il pourra lui aussi faire l'objet d'une relecture par un expert extérieur (qui devra là-encore signer un engagement de confidentialité).

Ce document sera mis en ligne sur le site institutionnel de la CNSA. Il pourra aussi être consulté par tout membre du GIS-IReSP.

Ces rapports permettent à la CNSA de **prendre connaissance** du projet et de ses **résultats de manière approfondie**, ce qui est indispensable pour qu'elle **appuie et oriente ses actions** sur ces connaissances. Ces rapports sont, par ailleurs, régulièrement mobilisés par la CNSA, en réponse à des sollicitations provenant d'autres institutions (ex : Inspection Générale des Affaires Sociales, Cour des comptes, …).

Le rapport scientifique complet doit présenter :

- le **contexte** et les **objectifs** de la recherche (si pertinent, les modifications des objectifs par rapport au projet initial) ;
- les **méthodologies** utilisées ;
- les **résultats** détaillés ;
- la **bibliographie ;**
- **les annexes**.

La **longueur** du rapport scientifique complet est à adapter selon l'envergure et la complexité du projet et doit satisfaire aux exigences attendues pour un rapport scientifique final de recherche. **Des publications scientifiques issues du projet peuvent constituer des parties du rapport si elles s'y prêtent. Elles doivent être intégrées en totalité dans le rapport. Si elles sont en anglais, au moins le résumé traduit en français doit être intégré dans le rapport et l'article mis en annexe.**

Les **supports visuels** (graphiques, tableaux etc.) permettant une meilleure compréhension du sujet sont appréciés.

Les **livrables** (brochures de présentation, capsules vidéo, thèses ou mémoires, articles soumis à des revues, articles publiés ou en cours de soumission, diaporamas en support d'une présentation orale, posters, etc…) réalisés au cours du projet doivent être transmis à l'IReSP à titre d'annexe(s).

Toute information confidentielle présentée dans ce rapport scientifique final et qui ne peut pas faire l'objet d'une divulgation aux destinataires mentionnés ou qui est sous embargo, doit être portée à la connaissance de l'IReSP.

Une date de fin d'embargo doit être communiquée pour une mise en ligne du rapport scientifique final sur le site de la CNSA.

1.2. Une partie sur la valorisation du travail et des résultats de la recherche

Cette section est destinée à répertorier l'ensemble des productions issues du projet, destinées à un public relevant du milieu académique ou non.

Elle sera transmise au(x) financeur(s)et pourra être consultée par tout membre du GIS-IReSP. Les liens renseignés pourront être relayés sur le site internet de l'IReSP.

2. La forme, le format et l'accessibilité du rapport

Sur la **forme**, il est demandé :

- que le document soit rédigé en police **Calibri 12** et **interligne simple ;**
- que les graphiques, tableaux, photographies etc. soient **légendés ;**
- **que les sauts de pages** intégrés dans ce document entre chaque section soit conservés afin de permettre une lecture facilitée du document et la consultation des différentes sections indépendamment les unes des autres ;
- de **conserver les mises en forme** proposées dans un soucis d'harmonisation des visuels.

Le rapport final de recherche devra être transmis en **format Word** à cette adresse suiviprojets.iresp@inserm.fr

Sur **l'accessibilité du contenu du rapport final de recherche aux personnes en situation de handicap.**

La mise en forme du rapport final accessible pour le public en situation de handicap est requise. Afin de rendre les contenus compréhensibles et utilisables par toutes personnes en situation de handicap, les rédacteurs sont invités à **consulter les recommandations nationales sur l'accessibilité numérique**. Les rédacteurs peuvent consulter, entre autres documentations, le « Kit d'accessibilité PDF, livret pédagogique »[1] développé par le programme de recherche Fractures. Ci-dessous sont listés quelques conseils.

- Le texte ne devra pas être « justifié » (mais aligné à gauche)
- Conserver les accents sur les majuscules (ex : À, É, etc.)
- Expliciter les abréviations et acronymes
- Déclarer tout changement de langue
- Insérer une description des images, graphiques utilisés dans le rapport
- Détailler les données des graphiques
- Utiliser des couleurs de texte contrastées
- Utiliser les niveaux de titres automatiques et générer, si besoin, une table des matières automatique

[1] https://www.fracturesnumeriques.fr/kit-accessibilite-pdf/livrets/livret_googledocs.pdf

I. PARTIE SCIENTIFIQUE

Résumé

Emploi, Parcours de soins et Autonomie des JEUnes adultes avec Paralysie cérébrale: données européennes

Catherine ARNAUD, Nicolas VIDART D'EGURBIDE BAGAZGOÏTIA

CONTEXTE
Les rôles sociaux des jeunes adultes avec paralysie cérébrale (PC) sont façonnés par une multiplicité de facteurs individuels, familiaux, environnementaux, et les expériences antérieures. Les questions de l'accès aux soins et de la satisfaction vis-à-vis des soins apparaissent cruciales à explorer tant elles sont associées au maintien d'une santé et d'une autonomie les plus optimales possible. L'emploi et la vie en communauté indépendante et autonome peuvent constituer des indicateurs d'une intégration effective dans la société.

OBJECTIFS
Chez les jeunes adultes avec PC : 1/ Documenter le statut vis-à-vis de l'emploi et, de manière plus globale, les différences de fréquence de participation avec la population générale ; 2/ Etudier les besoins de santé, l'accès aux soins et la satisfaction vis-à-vis des soins et leurs déterminants ; 3/ Evaluer le rôle médiateur de l'inadéquation de l'environnement dans la relation entre limitations fonctionnelles et restrictions de participation.

MÉTHODOLOGIE
Au total, 357 jeunes adultes (22-27 ans) avec PC, inclus dans SPARCLE3 (étude européenne observationnelle, portant sur l'impact de l'environnement sur la participation et la qualité de vie) ont rempli, seuls, avec aide ou par procuration, une série de questionnaires validés.

PRINCIPAUX RÉSULTATS
Notre étude a confirmé une participation significativement plus faible des jeunes adultes avec PC comparés à leurs pairs, avec des différences marquées pour les *Relations intimes* et l'*Indépendance*, modulées par la sévérité des déficiences. La focale sur l'emploi (35% étaient en emploi) a montré un bon niveau de satisfaction (rémunération, tâches adaptées aux capacités) et souligné l'importance d'une intégration antérieure dans une école ordinaire. La proportion de jeunes avec au moins un besoin de santé non satisfait variait de 21% à 49% en fonction du type de soins requis, sans impact sur la satisfaction pour les soins reçus mais modulée par le soutien des proches et des professionnels. La proportion de ceux déclarant un besoin environnemental non satisfait variait quant à elle de 1 à 53%. Alors que les besoins en *produits et technologies pour la mobilité* et le *soutien des proches* étaient fréquemment rapportés comme satisfaits, les besoins d'accessibilité de l'espace public, d'accès aux technologies de communication et aux informations étaient majoritairement non satisfaits. L'inadéquation de l'environnement dans les *Services, systèmes and politiques* renforçaient l'effet négatif des limitations fonctionnelles sur la participation.

APPORTS OU IMPACTS POTENTIELS
Cette étude apporte un nouvel éclairage sur les leviers d'action pour améliorer l'insertion sociale des jeunes adultes avec PC. Elle encourage la mise en œuvre de politiques d'inclusion dès le plus jeune âge, et souligne l'importance de l'environnement social et du soutien.

Abstract

Employment, care pathways and autonomy for young adults with cerebral palsy: a European study

Catherine ARNAUD, Nicolas VIDART D'EGURBIDE BAGAZGOÏTIA

CONTEXT
The social roles of young adults with cerebral palsy (CP) are shaped by a multiplicity of individual, family and environmental factors, as well as previous experiences. The issues of access to care and satisfaction with care appear to be crucial to explore, as they are associated with maintaining the best possible health and autonomy. Employment and independent, autonomous community living can be indicators of effective integration into society.

OBJECTIVES
Among young adults with CP, the aims were: 1/ To document employment status and, more generally, differences in frequency of participation with the general population; 2/ To study health needs, access to care and satisfaction with care and their determinants; 3/ To assess the mediating role of inadequacy of the environment in the relationship between functional limitations and participation restrictions.

METHODS
A total of 357 young adults (aged 22-27) with CP included in SPARCLE3 (a European observational study examining the impact of the environment on participation and quality of life) completed a series of validated questionnaires (self-, assisted self- or proxy reports).

MAIN RESULTS
Our study confirmed a significant lower participation in young adults with CP compared with their peers, with marked differences for Intimate Relationships and Independence, modulated by the severity of the impairments. The focus on employment (35% were in work) showed a good level of satisfaction (pay, tasks adapted to abilities) and highlighted the importance of prior integration into a mainstream school. The proportion of young people with at least one unmet health need varied from 21% to 49% depending on the type of care required, with no impact on satisfaction with the care received but modulated by support from family and professionals. The proportion of those declaring an unmet environmental need varied from 1% to 53%. While the need for products and technologies for mobility and support from relatives was frequently reported as satisfied, the need for accessibility of public spaces and access to communication technologies and information was mostly unsatisfied. The inadequacy of the environment in terms of services, systems and policies reinforced the negative effect of functional limitations on participation.

OUTCOMES OR POTENTIAL IMPACTS
This study sheds new light on the levers for action to improve the social integration of young adults with CP. It encourages the implementation of inclusive policies from an early age, and highlights the importance of the social environment and support.

Synthèse longue

Emploi, Parcours de soins et Autonomie des JEUnes adultes avec Paralysie cérébrale : données européennes
Catherine ARNAUD – CERPOP Inserm UMR1295, Université Toulouse III, Toulouse
Programme de recherche Autonomie 2020 – AAP Blanc
Cliquez ou appuyez ici pour entrer du texte.
Modalité du projet Projet de recherche complet Modalité du projet

Messages clés du projet

- La participation à la vie sociale est significativement plus faible pour les jeunes adultes avec paralysie cérébrale comparés à leurs pairs
- L'accès à l'emploi est fortement impacté par l'existence d'une intégration antérieure en école ordinaire
- Les besoins de santé non satisfaits peuvent concerner jusqu'à 1 jeune avec paralysie cérébrale sur 2, sans impact sur la satisfaction pour les soins reçus
- Les besoins en termes d'accessibilité de l'espace public, d'accès aux technologies de communication et aux informations sont majoritairement non satisfaits
- L'inadéquation de l'environnement dans les *Services, systèmes and politiques* renforce l'effet négatif des limitations fonctionnelles sur la participation

- le **contexte** et les **objectifs** du projet ;
- la **méthodologie** utilisée (deux pages maximum) ;
- les principaux **résultats** obtenus ;
- les **apports** potentiels de ces résultats pour la communauté de recherche ;
- la manière dont ces résultats peuvent éventuellement **alimenter les réflexions et actions** de **décideurs**,**acteurs nationaux ou locaux**, ainsi que des professionnels des secteurs sanitaire, médico-social, social ou autres acteur, le cas échéant ;
- Dans le cadre d'une **recherche interventionnelle** : les **conditions de transférabilité** ou de mise à l'échelle et les points de vigilance (⚠ si applicable) ;
- les **perspectives de recherches** ;
- les **15 principales références bibliographiques citées** en mettant en évidence, en caractères gras, les publications issues du projet (les autres publications issues du projet feront l'objet d'un recensement exhaustif dans la partie « Valorisation des résultats de la recherche »).

Contexte et objectifs :

L'entrée dans l'âge adulte est une phase de transition importante, particulièrement complexe pour les personnes avec handicap. Bien qu'elles bénéficient aujourd'hui de soins de plus en plus performants, de nouvelles technologies de communication et évoluent dans un contexte où les attitudes sociétales permettent l'inclusion dans tous les domaines de la vie,[1] elles continuent à faire face à de nombreux obstacles dans leur vie quotidienne. La littérature rapporte que, entre autres choses, les difficultés psychologiques, des interactions sociales fragmentées, une accessibilité limitée, des discriminations liées au handicap et le manque d'indépendance économique personnelle participent d'une insertion sociale limitée,[2–4] susceptible de perdurer tout au long de la vie. Un autre domaine de préoccupation est leur capacité à accéder aux ressources susceptibles d'améliorer leur autonomie, leur sentiment d'efficacité personnelle et leur santé.[5] À la différence de leurs pairs valides qui utilisent rarement le système de santé en tant que jeunes adultes, ceux qui présentent des handicaps de l'enfance tels que la paralysie cérébrale (PC) restent très dépendants de ce système.[6] Et bien qu'à cet âge ils souffrent d'une détérioration de leur mobilité et présentent douleurs chroniques, fatigue et problèmes de santé mentale à des fréquences élevées,[7–11] ils peuvent diminuer son utilisation, en partie parce que l'accès est rendu plus complexe avec la sortie du système pédiatrique caractérisé par des soins multiprofessionnels intégrés et une coordination efficace, et parce que la transition vers les services adultes est loin d'être optimale.[12–14]
Il est aujourd'hui admis qu'une intégration effective dans la société est bénéfique à tous points de vue. Facteurs individuels (santé, nature et sévérité des déficiences, temps disponible), familiaux (bonne santé et motivation des parents), ressources financières et organisationnelles à disposition pour répondre aux besoins, environnements adaptés et accessibles, sont autant d'éléments qui façonnent les rôles sociaux des jeunes adultes avec PC.[15] La littérature souligne également que les expériences antérieures de participation à la vie sociale, notamment dans l'enfance, peuvent être un point d'ancrage pour la participation future.[16] Cependant, cette participation sociale reste limitée et fortement dépendante du soutien parental ou familial.[4,17,18] En tant qu'adultes, les jeunes avec PC ont encore des opportunités de développement personnel insuffisantes[19] et une faible implication dans des activités significatives telles que l'emploi.[20,21] Ainsi, la scolarisation en milieu ordinaire et l'éducation inclusive[22,23] ne garantissent pas un accès effectif aux études supérieures, au marché du travail, à un travail rémunéré ou à un emploi stable et rémunéré de manière adéquate.[24–28]
Conformément au modèle conceptuel de l'Organisation Mondiale de la Santé (OMS) dans lequel le handicap résulte de l'inadéquation de l'environnement à la personne,[29] les relations entre environnement et participation ont été largement étudiées par le groupe européen SPARCLE (Study of PARticipation in Children with cerebral palsy Living in Europe).[30,31] Des différences marquées entre les pays participants dans les politiques publiques vis-à-vis du handicap et leur mise en œuvre, l'environnement physique social et attitudinal, les services de soutien et de soins, l'éducation ou l'accessibilité[32] ont permis de mieux comprendre dans quelle mesure un environnement non ou peu favorable affecte la

participation et les rôles sociaux. Dans cette étude, la population ciblée était celle d'enfants (première vague) et d'adolescents (deuxième vague de l'étude) avec PC. La PC est la principale cause de déficience physique à début précoce, survenant avec une fréquence d'environ 1,6 pour 1000 naissances.[33–35] Elle résulte de lésions non évolutives affectant le cerveau du fœtus ou du nouveau-né[36] conduisant à un ensemble de troubles impactant le mouvement et la posture. En plus des problèmes de mobilité, les personnes avec PC peuvent être affectées par un large éventail de difficultés expliquant la diversité des phénotypes.[37] La recherche internationale, qui s'est principalement focalisée sur l'enfance et l'adolescence, a démontré que la participation aux activités de vie des individus avec PC était très réduite par rapport à leurs pairs de la population générale, avec une augmentation croissante de cet écart avec la sévérité et le nombre de déficiences associées, ainsi qu'avec l'âge.[24,38–41] Toutefois, les recherches et les connaissances sur la participation sociale des adultes atteints de PC sont quasi-inexistantes alors même qu'aujourd'hui on estime que 90% des enfants atteints de cette pathologie devraient atteindre l'âge adulte.[34] L'emploi et la vie en communauté indépendante et autonome sont des indicateurs d'une intégration réussie dans la société.

L'emploi demeure l'un des domaines de vie dans lesquels les adultes atteints de PC subissent des restrictions de participation, avec des taux d'emploi variant entre 29% et 53%, largement inférieurs à ceux de la population générale des pays occidentaux.[14,42–45] A ce jour, peu de facteurs influant sur l'emploi des jeunes adultes atteints de PC ont été identifiés : la déficience intellectuelle et physique sévères, l'épilepsie et un niveau d'éducation inférieur.[14,20,24,44] Toutefois, de nombreux facteurs sont susceptibles d'influer sur l'accès à l'emploi : 1) les facteurs liés à la pathologie comme par exemple la motricité, les capacités cognitives, les possibilité d'une communication effective, la nécessité de disposer de plus de temps ou 2) les facteurs environnementaux tels que l'environnement au travail (nécessité d'adaptation, assistance), l'effectivité d'accès aux prestations de services, l'éducation (notamment les conditions de scolarisation en école ordinaire) ou bien les besoins et les disponibilités des éléments environnementaux (accessibilité par exemple), ou 3) la participation sociale. L'implication dans les activités de la vie quotidienne et récréative des enfants et adolescents est fortement limitée par la douleur, très fréquente et parfois intense,[46] et il est fortement probable que cette donnée soit retrouvée chez l'adulte. Par ailleurs, même si la PC résulte d'une lésion non progressive du cerveau, les conséquences de ces lésions sont susceptibles d'évoluer au cours du temps.[47] En parallèle de ces évolutions, la fatigue et la douleur sont extrêmement prévalentes et potentiellement des éléments freinateurs de l'intégration sociale. Ainsi, les soins prodigués tout au long du parcours de vie de l'enfance à l'adolescence pourraient influer plus ou moins directement sur l'ensemble des potentiels facteurs liés à l'emploi et seraient donc susceptible d'influer sur l'emploi. Toutefois aucune étude ne s'est intéressée à cette approche.

Les personnes avec handicaps doivent bénéficier de soins pluridisciplinaires continus pour maintenir leur santé et leur autonomie les plus optimales possible. Au-delà des soins, ils doivent pouvoir s'appuyer sur les services et ressources communautaires : services sociaux, emploi, logement, éducation, communication et mobilité pour accéder à un certain niveau de participation sociale, même s'ils restent bien souvent dépendants des membres de leur

famille. Par ailleurs, les challenges sont nombreux en quittant les réseaux de soins et de soutien pédiatriques - plus complets et surtout mieux coordonnés que ceux destinés aux adultes - pour entrer dans le système de santé pour adultes, plus fragmenté, et où la prise de décision médicale va incomber au jeune lui-même et non plus à ses parents. La question de l'accès aux soins, qui peut être approchée par des besoins de santé non satisfaits, et de la satisfaction vis-à-vis des soins, apparaissent donc cruciales à explorer tant elles sont associées à l'autonomie personnelle. Nous faisons l'hypothèse que des besoins de santé non satisfaits diminuent l'autonomie et participent de la restriction de participation. Nous considèrerons les facteurs environnementaux (accessibilité par exemples) et des facteurs cliniques (douleur, fatigue) comme potentiels freins à cet accès. Par ailleurs, la question des inégalités d'accès aux soins peut être posée du point de vue des inégalités socio-économiques. On sait que les personnes avec PC sont plus souvent issues de milieux socioéconomiques défavorisés que la population générale. Ces écarts pourraient être augmentés avec un accès à une autonomie financière difficile.

Ainsi, à partir de la base de données de la cohorte SPARCLE, ce projet avait initialement pour objectifs :

- (1) d'étudier l'accès à l'emploi des jeunes adultes avec PC en comparaison à la population générale du même âge, et d'en identifier les principaux freins dans les différents contextes européens, et (2) de déterminer les facteurs prédictifs d'un accès à l'emploi, au premier rang desquels les modes de scolarisation dans l'enfance, mais également le rôle de l'environnement, de facteurs personnels et de la participation.
- (3) de décrire l'utilisation des services de santé et les besoins en santé non satisfaits rapportés par les jeunes avec PC, et la satisfaction vis-à-vis de ces soins, et (4) d'explorer dans quelle mesure les facteurs personnels (sévérité du handicap, douleur, conditions de vie et position socioéconomique personnelle) et environnementaux (aides, accessibilité, attitudes) sont liés aux besoins non satisfaits.

L'obtention d'une bourse de thèse de doctorat en Epidémiologie par Célia Perret en octobre 2021 pour réaliser des travaux de recherche sur la mesure et le rôle médiateur de l'environnement chez les jeunes adultes avec PC, sur la base du modèle conceptuel de la Classification internationale du fonctionnement, du handicap et de la santé (CIF), a permis d'étendre les objectifs de PAJEUP. En effet, les adultes atteints de PC sont confrontés à des restrictions de participation plus importantes que la population générale dans divers aspects de leur vie. Selon la CIF, ces restrictions de participation résultent de déséquilibres dans les fonctions corporelles, les facteurs personnels et les facteurs environnementaux de l'individu, ce qui suggère qu'une modification d'une ou plusieurs de ces trois dimensions peut altérer ou améliorer la participation. Contrairement à certains facteurs fonctionnels ou personnels, l'environnement offre une plus grande adaptabilité, ce qui en fait un sujet d'étude essentiel pour améliorer la participation. Le travail conceptuel de l'ICF Core Set pour les adultes avec PC a permis d'identifier les facteurs environnementaux qui sont essentiels pour améliorer la participation des adultes atteints de PC. Les travaux conceptuels de la CIF ont suggéré le rôle médiateur de l'environnement dans le lien entre les limitations fonctionnelles et les restrictions de participation. En d'autres termes, un état de santé altéré peut générer

davantage de besoins environnementaux non satisfaits, qui à leur tour produisent des restrictions de participation. Pour autant, cet effet n'a, à ce jour, pas été étudié dans la littérature internationale, d'où l'objectif de ce travail de thèse.

La réponse à ces objectifs a conduit à développer sur ce programme trois axes de travail pour lesquels nous avons préparé six papiers (cinq publiés et un en cours de publication), quatre en position de leader (1er et dernier auteurs) et deux en position de collaborateur :

Axe 1 : Participation à la vie sociale des jeunes adultes avec PC, avec :
- Un premier papier s'intéressant à l'emploi et aux études supérieures des jeunes adultes avec PC (publié en 2023 dans le BMJ Public Health) ;
- Un papier s'intéressant aux différences de participation entre les jeunes adultes avec PC et la population générale (publié dans Disability and Health Journal en 2024).

Axe 2 : Besoins de santé, accès aux soins et satisfaction vis-à-vis des soins, avec :
- Un papier s'intéressant au lien entre besoins environnementaux non satisfaits et besoins de santé non satisfaits (publié dans Frontiers in Rehabilitation Sciences en 2024) ;
- Un papier s'intéressant à la satisfaction vis-à-vis des soins de santé chez les jeunes adultes avec PC (publié dans Frontiers in Medicine en 2024).

Axe 3 : Rôle de l'environnement : mesure et lien avec la participation
- Un papier évaluant dans quelle mesure l'European Adult Environment Questionnaire (EAEQ), développé au cours de la 3ème vague de SPARCLE et mesurant l'environnement des jeunes adultes avec PC, couvre la CIF, et décrivant l'adéquation de l'environnement physique, social et attitudinal aux besoins spécifiques des jeunes adultes avec PC (publié en 2024 dans Archives of Physical Medicine and Rehabilitation) ;

Méthodologie :

Nous avons utilisé les données de SPARCLE3, une étude observationnelle multicentrique européenne, conçue pour étudier l'impact de l'environnement sur la participation et la qualité de vie des jeunes adultes atteints de PC, et déterminer les facteurs prédictifs d'une vie de jeune adulte réussie dans les domaines de l'éducation, de la profession, de la santé et de la société. La conception de l'étude a été décrite en détails par ailleurs.[48]

Echantillon de l'étude :

La population éligible était composée de jeunes adultes, âgés de 22 à 27 ans au moment de la collecte des données en 2018-2020, avec un diagnostic de PC selon la définition du réseau Surveillance of Cerebral Palsy in Europe. Ils vivaient en France, Allemagne, Suède et Italie pour ceux qui avaient déjà participé à la cohorte SPARCLE en tant qu'enfants (âgés de 8 à 12 ans en 2004-2005, SPARCLE1) et/ou adolescents (âgés de 13 à 17 ans en 2009-2010, SPARCLE2). Un échantillon additionnel d'individus a été invité à participer dans toutes les régions, auquel s'est ajouté un nouveau centre au Portugal. L'échantillon total était de 310 sujets, dont 164 avaient participé aux vagues précédentes de la cohorte SPARCLE.

En France et en Allemagne, un groupe témoin de jeunes adultes de la même tranche d'âge a été recruté à l'aide d'une enquête en ligne. Les participants à l'enquête ont reçu des incitations de la part d'un panéliste qui a recruté des hommes et des femmes (dans une

proportion de 50%/50%) âgés de 19 à 29 ans et vivant dans l'un des deux pays participants (France : n = 2080 ; Allemagne : n = 1964).

Approbation éthique et consentement de participation :

Les autorisations éthiques et réglementaires ont été obtenues dans chaque pays. Tous les jeunes avec PC ou leurs représentants légaux ont donné leur consentement éclairé de participation ou leur non-opposition le cas échéant.

Recueil de données :

Des enquêteurs formés ont rendu visite aux jeunes adultes avec PC et ont mené des entretiens dans des conditions identiques dans chaque région. Dans la mesure du possible, les questionnaires ont été remplis par les intéressés eux-mêmes, avec l'aide du chercheur si nécessaire. Lorsque cela n'était pas possible, les questionnaires ont été complétés par une tierce personne (parent, assistant personnel ou partenaire) impliquée de manière significative dans la vie quotidienne de la personne avec PC et servant de proxy.

Les enquêteurs ont recueilli des informations standardisées sur les **déficiences et les comorbidités** : capacité de marche, motricité fine, déficience visuelle, capacité d'élocution et performance de communication. Les capacités intellectuelles ont été évaluées à l'inclusion à l'aide d'un test de QI formel ou d'un algorithme basé sur une série de questions posées à des proches [12]. Les jeunes adultes ont également fait état de leur fatigue au cours des deux dernières semaines et des crises d'épilepsie survenues au cours de l'année précédant l'entretien. Nous avons également recueilli des **facteurs contextuels personnels et familiaux** : taille de la population de la zone de résidence, mode de vie, niveau d'éducation personnel et parental le plus élevé et richesse perçue.

La **participation à la vie sociale** a été évaluée à l'aide du Questionnaire of Young People's Participation – Young Adults (QYPP-YA). Lors de l'entretien, il a été demandé aux jeunes adultes avec PC s'ils avaient un emploi, s'ils poursuivaient leurs études ou s'ils étaient au chômage, et recueilli des informations sur leur niveau d'éducation le plus élevé. Le questionnaire WHOQOL-Bref a été utilisé pour mesurer la **qualité de vie** (scores de 0 à 100, les scores les plus élevés indiquant une meilleure qualité de vie) dans quatre domaines : le bien-être physique, le bien-être psychologique, les relations sociales et l'environnement.

Les **besoins et la couverture en matière de soins de santé** ont été évalués à l'aide du questionnaire Youth Health Care, Satisfaction, Utilization and Needs (YHC-SUN). Un second module de 7 items a permis le recueil de la satisfaction vis-à-vis des soins de santé.

L'environnement physique, social et attitudinal a été appréhendé à l'aide de l'EAEQ, qui évalue 61 facteurs environnementaux (FE). Deux types d'informations étaient disponibles : le besoin du FE et sa couverture en cas de besoin, ou seulement sa couverture lorsque le besoin était considéré *a priori* comme commun à tous les individus. Les réponses ont été catégorisées comme "besoin environnemental non satisfait" lorsque la réponse "Besoin manifesté et non couvert" a été fournie, et "besoin environnemental satisfait" lorsque les réponses "Pas de besoin manifesté" ou "Besoin manifesté et couvert" ont été cochées, en fonction de l'item.

Analyses statistiques

Emploi et études supérieures : Pour cette analyse, nous avons restreint notre échantillon aux adultes avec PC, âgés de 22 à 27 ans, sans déficience intellectuelle modérée à profonde.

L'analyse a été effectuée séparément pour les statuts d'emploi et d'enseignement supérieur. Nous avons effectué des régressions logistiques inconditionnelles pour estimer les odds ratio (OR) et les intervalles de confiance à 95 % (IC 95 %) afin d'évaluer les associations avec les facteurs personnels, sociodémographiques et environnementaux.
Différences de participation avec la population générale : Nous avons comparé la participation des jeunes adultes avec PC à celle de leurs pairs de la population générale à l'aide d'un modèle expliquant les scores latents de participation par le statut de PC, ajusté pour les facteurs de confusion identifiés dans la population non atteinte de PC.
Accès aux soins : Nous avons effectué des régressions logistiques pour estimer les OR et leurs IC 95% qui mesurent les associations entre les besoins environnementaux non satisfaits dans chaque domaine (physique, social et attitudinal) et les besoins non satisfaits en physiothérapie, ergothérapie, orthophonie et accompagnement psychologique.
Satisfaction vis-à-vis des soins : Nous avons utilisé des analyses de corrélation pour explorer les associations entre la satisfaction à l'égard des soins de santé et les indicateurs respectifs liés à la disponibilité et à l'accessibilité des services de santé ainsi qu'à la sévérité des déficiences.
Mesure de l'inadéquation de l'environnement : Des FE pertinents pour les jeunes adultes atteints de PC ont été identifiés lors de focus groups en Angleterre et au Portugal. Les FE ont été mis en correspondance avec la classification environnementale de la CIF et la structure analytique de l'EAEQ a résulté de cette procédure de mise en relation. La validité du contenu a été évaluée à l'aide du bandwidth index (pourcentage de couverture de l'ICF Core Sets pour les adultes avec PC). Une analyse descriptive a été réalisée.

Principaux résultats et apports :

Emploi et Etudes supérieures :

Nous avons montré que 45,4 % des jeunes adultes atteints de PC et ayant un QI ≥50 ne suivaient pas d'études supérieures et n'avaient pas d'emploi. Parmi ceux qui avaient un emploi (35,2 %), plus de 4 sur 5 déclaraient être rémunérés, se voir confier des tâches adaptées à leurs capacités ou être satisfaits de leur capacité de travail. La probabilité d'avoir un emploi était significativement réduite (de plus de 75 %) pour les jeunes souffrant de graves limitations de la motricité globale ou de graves difficultés de communication, par rapport aux participants moins gravement handicapés. La probabilité d'obtenir un diplôme de l'enseignement supérieur était réduite d'un facteur de 0,19 pour les jeunes souffrant de déficiences motrices graves et de 0,02 pour ceux dont la parole est imprécise ou incompréhensible. Le fait d'être diplômé de l'enseignement supérieur et d'avoir fréquenté une école ordinaire pendant l'enfance, ou d'avoir poursuivi une scolarité ordinaire jusqu'à l'adolescence, s'est avéré être un puissant levier pour l'accès à l'emploi (les chances d'être employé ont été multipliées par 12 et 16, respectivement). À l'exception de l'accessibilité à un parking en cas de besoin, aucun des facteurs environnementaux étudiés n'a influencé de manière significative l'emploi ou le statut d'étudiant dans l'enseignement supérieur, après ajustement pour les déficiences. Les jeunes adultes ayant un emploi ont fait état d'un bien-être physique et psychologique significativement plus élevé que ceux qui n'en avaient pas.

Cette étude apporte un nouvel éclairage sur les barrières et les leviers d'accès à l'emploi ou à l'enseignement supérieur chez les jeunes adultes avec PC. Nous avons montré que les déficiences sévères de la motricité et de la communication sont les deux principaux facteurs qui limitent l'emploi ou l'achèvement de l'enseignement supérieur. Si nous complétons les

données existantes sur le rôle de l'enseignement supérieur dans l'accès à l'emploi, nous sommes les premiers à étudier et à observer que le fait d'avoir fréquenté une école ordinaire pendant l'enfance ou d'avoir poursuivi une scolarité ordinaire jusqu'à l'adolescence est un puissant levier pour l'accès à l'emploi. A notre connaissance, cette étude est la première à examiner les associations entre l'environnement et l'emploi et l'enseignement supérieur, et à rapporter le rôle positif de l'accessibilité à un parking en cas de besoin sur l'emploi ou le statut dans l'enseignement supérieur. Enfin, nous sommes les premiers à rapporter l'impact positif de l'emploi sur la qualité de vie physique et psychologique de jeunes adultes atteints de paralysie cérébrale. De façon générale, les études portant sur les jeunes adultes avec PC montrent que leur accès à l'emploi peut encore être améliorée. Nos résultats suggèrent que l'inclusion des jeunes handicapés dans la société dès leur plus jeune âge et leur maintien autant que possible dans cette position favorisent leur accès à l'enseignement supérieur et à l'emploi à l'âge adulte. Compte tenu de l'impact positif de l'emploi sur leur qualité de vie, cela encourage la mise en œuvre de politiques d'inclusion dès le plus jeune âge.

Différences de participation entre les jeunes adultes avec PC et leurs pairs de la population générale :

Au cours de la dernière décennie, la participation est apparue comme une problématique essentielle de la recherche sur le handicap. Notre étude a montré une participation significativement plus faible dans les cinq domaines étudiés (Relations intimes, Relations interpersonnelles, Vie sociale, Indépendance et Autonomie) chez les jeunes adultes avec PC comparés à leurs pairs non atteints de PC. Les domaines des Relations intimes et de l'Indépendance présentaient les différences les plus importantes ($\beta = 1,71$; IC95% [1,46 ; 1,95] et $\beta = 1,24$; IC95% [1,02 ; 1,24], respectivement). Cependant, ces effets semblaient modérés par le niveau de sévérité des déficiences des jeunes adultes avec PC. En effet, les jeunes adultes avec les déficiences les moins sévères (GMFCS I-II-III et BFMF I-II-III) ne présentaient aucune différence avec leurs pairs de la population générale en ce qui concerne les Relations interpersonnelles, la Vie sociale et l'Indépendance, mais ils prenaient plus souvent des décisions autonomes dans la vie quotidienne que leurs pairs. Nous avons également observé que la poursuite des études pourrait contribuer à réduire la différence de participation dans les domaines des Relations interpersonnelles et de l'Indépendance, et que les femmes semblaient avoir des différences de participation avec leurs pairs de la population générale en termes d'Indépendance plus importantes que les hommes.

De façon générale, notre étude étend les connaissances sur les restrictions de participation chez les jeunes adultes avec PC. Des études antérieures menées pendant l'enfance et l'adolescence ont également fait état de désavantages, sauf dans des domaines spécifiques tels que l'utilisation de jeux électroniques.[41] Nos résultats confirment ceux de Wiegerink et al.[19] selon lesquels les jeunes adultes atteints de PC ont moins de relations intimes que leurs pairs non atteints de PC. L'étude qualitative menée pour développer le QYPP-YA a mis en évidence les difficultés à rencontrer un partenaire, en particulier pour les jeunes ayant un handicap plus sévère et nécessitant une assistance. Pour Friedman [49] , ils peuvent souffrir d'un manque d'intimité dû à leurs conditions de logement et au nombre de colocataires, ainsi qu'à l'attitude généralement négative des membres de la famille et des professionnels à l'égard de leur sexualité. Michelsen [41] a montré que les adolescents atteints de PC passaient moins de temps seuls avec leurs amis sans la supervision d'un adulte et moins de temps avec leurs petits amis.

Un autre résultat de cette étude est l'effet médiateur de la scolarisation sur les différences de participation. L'éducation peut développer l'indépendance dans les choix de vie et les relations interpersonnelles. Ce résultat est conforme au travail de Wiegerink et al.[19] et soutient l'effet positif des contacts mixtes avec les pairs. Néanmoins, notre étude transversale n'a pas pu démontrer la relation de cause à effet entre la poursuite des études et la participation à l'autonomie ou aux relations interpersonnelles. En revanche, nous avons observé que l'éducation joue un rôle médiateur dans la différence de participation dans le domaine des Relations intimes. Le petit nombre de jeunes atteints de PC qui poursuivent leurs études entre 19 et 28 ans réduit l'écart de participation par rapport à leurs pairs non atteints de PC. En tout état de cause, la poursuite des études est essentielle pour de meilleures opportunités professionnelles et pour le développement social. Elle devrait être encouragée pour les jeunes atteints de PC. En outre, la société doit investir dans une éducation véritablement inclusive, dans l'égalité des chances et dans des systèmes d'éducation individualisés pour les jeunes avec un handicap dès le plus jeune âge et ce jusqu'à l'âge adulte.

Accès aux soins :

Notre étude a montré que le besoin de soins le plus courant était la physiothérapie, signalé par plus de quatre jeunes adultes avec PC sur cinq. Parmi ceux qui ont exprimé un besoin de soins, la proportion de ceux dont le besoin n'a pas été satisfait varie en fonction du type de soins requis : 20,8 % à 48,5 % pour la rééducation, et 40,3 % pour l'accompagnement psychologique. Nous avons trouvé une association entre un environnement inadapté aux besoins spécifiques des jeunes atteints de PC et leurs besoins de soins. Plus précisément, l'accumulation de besoins non satisfaits dans l'environnement social, explorant le soutien de l'assistant personnel, de la famille et des amis, du personnel de santé et des collègues, et des étrangers, était associée à des besoins non satisfaits dans tous les domaines de santé explorés, même en tenant compte de la gravité des déficiences et des caractéristiques sociodémographiques des individus. L'absence d'attitudes de soutien multipliait par plus de trois le risque de signaler également un besoin non satisfait d'orthophonie et de physiothérapie, uniquement chez les personnes dont la fonction motrice globale était la plus gravement altérée dans ce dernier cas. Enfin, notre étude n'a montré aucune association entre les besoins non satisfaits dans l'environnement physique et les besoins non satisfaits en matière de soins de santé.

À notre connaissance, aucune publication n'a spécifiquement évalué la relation entre les besoins de santé non satisfaits des jeunes adultes avec PC et l'adéquation de leur environnement à leurs besoins spécifiques. Nos résultats soulignent l'importance de l'environnement social et du soutien. À cet âge, une plus grande indépendance et émancipation, notamment vis-à-vis des parents, pourrait expliquer en partie pourquoi les jeunes adultes ont des besoins de santé non satisfaits plus importants que les enfants. On peut émettre l'hypothèse que l'absence d'association entre l'environnement physique et les besoins de santé non satisfaits est due au fait qu'un environnement physique peu adéquat est souvent compensé par le soutien social et l'aide de la famille et des amis. Ainsi, un jeune adulte pourrait se déplacer facilement s'il est accompagné, même dans un environnement moins adapté, alors qu'un individu moins soutenu aurait plus de difficultés même dans un environnement physique mieux adapté. Il est également concevable que cette différence soit liée aux déficiences cognitives, qui posent souvent plus de défis à la mobilité

indépendante que les déficiences motrices, pour lesquelles des adaptations sont généralement possibles. Nos résultats suggèrent que plus les besoins non satisfaits dans l'environnement social sont importants, plus les besoins non satisfaits en matière de soins de santé pour l'ergothérapie, l'orthophonie et l'accompagnement psychologique sont importants. Cependant, en raison du petit nombre de participants présentant de multiples besoins non satisfaits dans leur environnement social, ces résultats doivent être interprétés avec prudence. Nos résultats indiquent que peu de soutien attitudinal est associé à des besoins de soins de santé non satisfaits en orthophonie, qui concerne la plupart des personnes atteintes de déficiences motrices et cognitives graves, et en physiothérapie pour les personnes atteintes de déficiences motrices graves. Cela suggère que ce soutien est particulièrement crucial pour garantir l'accès aux soins de santé pour ces thérapies chez les jeunes adultes gravement handicapés avec PC. Nous n'avons pas trouvé cette association chez les personnes qui avaient besoin d'ergothérapie ou d'accompagnements psychologiques.

Satisfaction vis-à-vis des soins :

Notre étude a exploré les besoins non satisfaits en matière de soins de santé chez les jeunes adultes avec PC et la manière dont ils sont associés à l'insatisfaction à l'égard des soins de santé. Nous avons supposé que le manque d'accès aux soins de santé, identifié par les besoins non satisfaits en matière de soins de santé, est associé à l'insatisfaction à l'égard des soins de santé.

La satisfaction à l'égard des soins de santé était modérée à bonne et presque systématiquement plus élevée pour l'échantillon de jeunes adultes avec PC que pour les jeunes adultes issus de la population générale. Les associations entre la satisfaction à l'égard des soins de santé et la sévérité des déficiences fonctionnelles n'étaient pas significatives. Par ailleurs, dans cette analyse, la satisfaction à l'égard des services de santé était similaire à celle de l'échantillon de population générale du même âge. Plusieurs facteurs peuvent jouer un rôle : le recrutement dans l'enquête auprès de la population générale n'excluait aucune autre maladie chronique. Nous supposons également que les jeunes adultes moins exposés et ayant moins d'interactions avec les prestataires de soins de santé peuvent être plus critiques, tandis que les jeunes adultes avec PC sont susceptibles d'entretenir des relations positives durables avec au moins certains professionnels de santé. Une plus grande implication pourrait conduire à une meilleure appréciation des services reçus. En outre, la satisfaction à l'égard des soins de santé n'était pas associée à l'utilisation des services de santé ou aux besoins (non satisfaits) en matière de soins de santé. Ainsi, les besoins non satisfaits et la satisfaction à l'égard des soins de santé semblent ne pas être liés.

La littérature dans ce domaine est massivement centrée sur la période de la transition, souvent brutale, des centres de soins de santé pluriprofessionnels intégrés, généralement bien équipés, disponibles pour les enfants et les adolescents, aux soins beaucoup plus fragmentés à l'âge adulte. Une métanalyse a souligné les mauvais résultats globaux obtenus à cette période, notamment l'instabilité du logement, le chômage, la difficulté à nouer des relations, l'augmentation des taux d'admission à l'hôpital et la diminution de l'utilisation des services de réadaptation. [36] Les facteurs associés à l'amélioration des résultats comprennent la participation de la famille, la promotion de l'auto-efficacité et la rencontre de l'équipe adulte avant la transition. [7] Les résultats que nous avons obtenus, de manière originale, sur une population déjà partiellement orientée dans le système adulte, montrent

que les besoins non satisfaits n'ont pas d'impact sur la satisfaction des soins de santé que ces patients reçoivent, et soulignent la nécessité de se concentrer non seulement sur la couverture des besoins mais également sur la satisfaction vis-à-vis des soins.

Mesure de l'inadéquation de l'environnement :

L'EAEQ est questionnaire de 61 items, développé dans le cadre de l'étude SPARCLE3 pour mesurer l'adéquation de l'environnement aux besoins individuels des jeunes adultes avec PC. Les facteurs environnementaux pertinents pour les jeunes adultes avec PC ont été identifiés lors de groupes de discussion en Angleterre et au Portugal, et, dans un travail préliminaire, mis en correspondance avec la classification environnementale de la CIF. L'analyse a montré une couverture élevée des items de la classification environnementale de la CIF (79,3%), ce qui a permis d'obtenir une validité de contenu satisfaisante. Le questionnaire a été organisé en cinq chapitres basés sur les chapitres de la CIF : « produits et technologies » (19 items), « soutien et relations » (8 items), « attitudes » (6 items), « systèmes et politiques de service » (22 items) et « comprendre et être compris » (6 items).

Lors de notre exploration descriptive, nous avons montré que la proportion de besoins environnementaux non satisfaits varie selon les chapitres. De façon plutôt positive, nous avons observé de faibles proportions de besoins non satisfaits relatifs aux « soutiens et relations » et aux « attitudes » (<10%) qui concernent plutôt des données proximales. Au contraire, ceux liés aux « systèmes et politiques de service » et « produits et technologie » correspondent moins bien aux besoins (10-20% de besoins non satisfaits). De tous les services explorés, ceux liés à la communication et à l'information correspondaient très mal aux besoins. Il a déjà été démontré que la fourniture d'informations appropriées et l'accès aux technologies de communication améliorent la vie des personnes handicapées et favorisent une véritable inclusion dans la société. [47] Enfin, de façon générale, on retrouvait plus de besoins environnementaux non satisfaits chez les femmes et les jeunes présentant une atteinte sévère des fonctions motrices (GMFCS IV-V).

Ce questionnaire EAEQ permet de collecter les FE utiles aux personnes avec PC et d'analyser si leur disponibilité, leur modification ou leur adaptation pourrait améliorer la réalisation des activités quotidiennes, la participation et la qualité de vie. Malgré le grand nombre d'items, qui pourrait rendre le questionnaire fastidieux à remplir, nous avons observé un taux de réponse élevé pour tous les items (plus de 96%), ce qui souligne son acceptabilité. Cela suggère la possibilité d'une utilisation généralisée dans la pratique clinique. En mesurant systématiquement un large éventail de FE, les professionnels de la santé pourraient se faire une idée précise de l'étendue des besoins de leurs patients et les aider à apporter les compensations nécessaires. L'analyse des différences géographiques ou temporelles de fréquence de participation ou de niveau de qualité de vie, couplée à une vision globale des besoins environnementaux non satisfaits, pourrait fournir aux pouvoirs publics les éléments d'une politique d'accessibilité et d'intégration des personnes handicapées dans la société. Enfin, la mesure indépendante de l'environnement ouvre de nouvelles voies pour l'étude des associations entre l'environnement et une série d'indicateurs de résultats rapportés par les patients (Patient Reported Outcomes Measures), insuffisamment connus et utilisés en France, et ceci de manière complémentaire à ceux rapportés par les professionnels, comme recommandé par la Haute Autorité de Santé.

Articles issus de ce travail

Vidart d'Egurbide Bagazgoïtia N, Perret C, Himmelmann K, Thyen U, Ehlinger V, Duffaut C, Arnaud C, Sentenac M. **Employment and higher education in young adults with cerebral palsy: a cross-sectional analysis of the SPARCLE study.** BMJ Public Health 2023;1:e000141. https://doi.org/10.1136/bmjph-2023-000141

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Note: contributeurs de l'équipe (par ordre alphabétique)
Arnaud C, Delobel M, Duffaut C, Ehlinger V, Perret C, Rioual J, Sentenac M, Vidart d'Egurbide Bagazgoïtia N

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S'il s'agit d'un **projet d'amorçage, projet pilote, contrat de définition** ou de soutien à la **mise en place de projets européens :**
Ce projet a-t-il permis de construire un projet de recherche complet ?

☐Oui ☐Non

Si non, précisez les raisons :

Si oui, <u>précisez bien dans la synthèse</u> les perspectives : projet envisagé, conditions de faisabilité, principaux points d'attention et perspectives de financement.

Rapport scientifique complet

Rappel : Ce document n'est requis que pour les projets soutenus par la CNSA

Emploi, Parcours de soins et Autonomie des JEUnes adultes avec Paralysie cérébrale : données européennes
Catherine ARNAUD – CERPOP UMR1295, Inserm, Université Toulouse III, Toulouse
Projet de recherche Autonomie 2020 – AAP Blanc
Cliquez ou appuyez ici pour entrer du texte.
Modalité du projet Projet de recherche complet Modalité du projet

Contexte et objectifs :

L'entrée dans l'âge adulte est une phase de transition importante, particulièrement complexe pour les personnes avec handicap. Bien qu'elles bénéficient aujourd'hui de soins de plus en plus performants, de nouvelles technologies de communication et évoluent dans un contexte où les attitudes sociétales permettent l'inclusion dans tous les domaines de la vie,[1] elles continuent à faire face à de nombreux obstacles dans leur vie quotidienne. La littérature rapporte que, entre autres choses, les difficultés psychologiques, des interactions sociales fragmentées, une accessibilité limitée, des discriminations liées au handicap et le manque d'indépendance économique personnelle participent d'une insertion sociale limitée,[2–4] susceptible de perdurer tout au long de la vie. Un autre domaine de préoccupation est leur capacité à accéder aux ressources susceptibles d'améliorer leur autonomie, leur sentiment d'efficacité personnelle et leur santé.[5] À la différence de leurs pairs valides qui utilisent rarement le système de santé en tant que jeunes adultes, ceux qui présentent des handicaps de l'enfance tels que la paralysie cérébrale (PC) restent très dépendants de ce système.[6] Et bien qu'à cet âge ils souffrent d'une détérioration de leur mobilité et présentent douleurs chroniques, fatigue et problèmes de santé mentale à des fréquences élevées,[7–11] ils peuvent diminuer son utilisation, en partie parce que l'accès est rendu plus complexe avec la sortie du système pédiatrique caractérisé par des soins multiprofessionnels intégrés et une coordination efficace, et parce que la transition vers les services adultes est loin d'être optimale.[12–14]
Il est aujourd'hui admis qu'une intégration effective dans la société est bénéfique à tous points de vue. Facteurs individuels (santé, nature et sévérité des déficiences, temps disponible), familiaux (bonne santé et motivation des parents), ressources financières et organisationnelles à disposition pour répondre aux besoins, environnements adaptés et accessibles, sont autant d'éléments qui façonnent les rôles sociaux des jeunes adultes avec PC.[15] La littérature souligne également que les expériences antérieures de participation à la vie sociale, notamment dans l'enfance, peuvent être un point d'ancrage pour la participation future.[16] Cependant, cette participation sociale reste limitée et fortement dépendante du soutien parental ou familial.[4,17,18] En tant qu'adultes, les jeunes avec PC ont encore des opportunités de développement personnel insuffisantes[19] et une faible implication dans des activités significatives telles que l'emploi.[20,21] Ainsi, la scolarisation en milieu ordinaire et l'éducation inclusive[22,23] ne garantissent pas un accès effectif aux études supérieures, au marché du travail, à un travail rémunéré ou à un emploi stable et rémunéré de manière adéquate.[24–28]
Conformément au modèle conceptuel de l'Organisation Mondiale de la Santé (OMS) dans lequel le handicap résulte de l'inadéquation de l'environnement à la personne,[29] les relations entre environnement et participation ont été largement étudiées par le groupe européen SPARCLE (Study of PARticipation in Children with cerebral palsy Living in Europe).[30,31] Des différences marquées entre les pays participants dans les politiques publiques vis-à-vis du handicap et leur mise en œuvre, l'environnement physique social et attitudinal, les services de soutien et de soins, l'éducation ou l'accessibilité[32] ont permis de mieux comprendre dans quelle mesure un environnement non ou peu favorable affecte la

participation et les rôles sociaux. Dans cette étude, la population ciblée était celle d'enfants (première vague) et d'adolescents (deuxième vague de l'étude) avec PC. La PC est la principale cause de déficience physique à début précoce, survenant avec une fréquence d'environ 1,6 pour 1000 naissances.[33–35] Elle résulte de lésions non évolutives affectant le cerveau du fœtus ou du nouveau-né[36] conduisant à un ensemble de troubles impactant le mouvement et la posture. En plus des problèmes de mobilité, les personnes avec PC peuvent être affectées par un large éventail de difficultés expliquant la diversité des phénotypes.[37] La recherche internationale, qui s'est principalement focalisée sur l'enfance et l'adolescence, a démontré que la participation aux activités de vie des individus avec PC était très réduite par rapport à leurs pairs de la population générale, avec une augmentation croissante de cet écart avec la sévérité et le nombre de déficiences associées, ainsi qu'avec l'âge.[24,38–41] Toutefois, les recherches et les connaissances sur la participation sociale des adultes atteints de PC sont quasi-inexistantes alors même qu'aujourd'hui on estime que 90% des enfants atteints de cette pathologie devraient atteindre l'âge adulte.[34] L'emploi et la vie en communauté indépendante et autonome sont des indicateurs d'une intégration réussie dans la société.

L'emploi demeure l'un des domaines de vie dans lesquels les adultes atteints de PC subissent des restrictions de participation, avec des taux d'emploi variant entre 29% et 53%, largement inférieurs à ceux de la population générale des pays occidentaux.[14,42–45] A ce jour, peu de facteurs influant sur l'emploi des jeunes adultes atteints de PC ont été identifiés : la déficience intellectuelle et physique sévères, l'épilepsie et un niveau d'éducation inférieur.[14,20,24,44] Toutefois, de nombreux facteurs sont susceptibles d'influer sur l'accès à l'emploi : 1) les facteurs liés à la pathologie comme par exemple la motricité, les capacités cognitives, les possibilité d'une communication effective, la nécessité de disposer de plus de temps ou 2) les facteurs environnementaux tels que l'environnement au travail (nécessité d'adaptation, assistance), l'effectivité d'accès aux prestations de services, l'éducation (notamment les conditions de scolarisation en école ordinaire) ou bien les besoins et les disponibilités des éléments environnementaux (accessibilité par exemple), ou 3) la participation sociale. L'implication dans les activités de la vie quotidienne et récréative des enfants et adolescents est fortement limitée par la douleur, très fréquente et parfois intense,[46] et il est fortement probable que cette donnée soit retrouvée chez l'adulte. Par ailleurs, même si la PC résulte d'une lésion non progressive du cerveau, les conséquences de ces lésions sont susceptibles d'évoluer au cours du temps.[47] En parallèle de ces évolutions, la fatigue et la douleur sont extrêmement prévalentes et potentiellement des éléments freinateurs de l'intégration sociale. Ainsi, les soins prodigués tout au long du parcours de vie de l'enfance à l'adolescence pourraient influer plus ou moins directement sur l'ensemble des potentiels facteurs liés à l'emploi et seraient donc susceptible d'influer sur l'emploi. Toutefois aucune étude ne s'est intéressée à cette approche.

Les personnes avec handicaps doivent bénéficier de soins pluridisciplinaires continus pour maintenir leur santé et leur autonomie les plus optimales possible. Au-delà des soins, ils doivent pouvoir s'appuyer sur les services et ressources communautaires : services sociaux, emploi, logement, éducation, communication et mobilité pour accéder à un certain niveau de participation sociale, même s'ils restent bien souvent dépendants des membres de leur

famille. Par ailleurs, les challenges sont nombreux en quittant les réseaux de soins et de soutien pédiatriques - plus complets et surtout mieux coordonnés que ceux destinés aux adultes - pour entrer dans le système de santé pour adultes, plus fragmenté, et où la prise de décision médicale va incomber au jeune lui-même et non plus à ses parents. La question de l'accès aux soins, qui peut être approchée par des besoins de santé non satisfaits, et de la satisfaction vis-à-vis des soins, apparaissent donc cruciales à explorer tant elles sont associées à l'autonomie personnelle. Nous faisons l'hypothèse que des besoins de santé non satisfaits diminuent l'autonomie et participent de la restriction de participation. Nous considèrerons les facteurs environnementaux (accessibilité par exemples) et des facteurs cliniques (douleur, fatigue) comme potentiels freins à cet accès. Par ailleurs, la question des inégalités d'accès aux soins peut être posée du point de vue des inégalités socio-économiques. On sait que les personnes avec PC sont plus souvent issues de milieux socioéconomiques défavorisés que la population générale. Ces écarts pourraient être augmentés avec un accès à une autonomie financière difficile.

Ainsi, à partir de la base de données de la cohorte SPARCLE, ce projet avait initialement pour objectifs :

- (1) d'étudier l'accès à l'emploi des jeunes adultes avec PC en comparaison à la population générale du même âge, et d'en identifier les principaux freins dans les différents contextes européens, et (2) de déterminer les facteurs prédictifs d'un accès à l'emploi, au premier rang desquels les modes de scolarisation dans l'enfance, mais également le rôle de l'environnement, de facteurs personnels et de la participation.
- (3) de décrire l'utilisation des services de santé et les besoins en santé non satisfaits rapportés par les jeunes avec PC, et la satisfaction vis-à-vis de ces soins, et (4) d'explorer dans quelle mesure les facteurs personnels (sévérité du handicap, douleur, conditions de vie et position socioéconomique personnelle) et environnementaux (aides, accessibilité, attitudes) sont liés aux besoins non satisfaits.

L'obtention d'une bourse de thèse de doctorat en Epidémiologie par Célia Perret en octobre 2021 pour réaliser des travaux de recherche sur la mesure et le rôle médiateur de l'environnement chez les jeunes adultes avec PC, sur la base du modèle conceptuel de la Classification internationale du fonctionnement, du handicap et de la santé (CIF), a permis d'étendre les objectifs de PAJEUP. En effet, les adultes atteints de PC sont confrontés à des restrictions de participation plus importantes que la population générale dans divers aspects de leur vie. Selon la CIF, ces restrictions de participation résultent de déséquilibres dans les fonctions corporelles, les facteurs personnels et les facteurs environnementaux de l'individu, ce qui suggère qu'une modification d'une ou plusieurs de ces trois dimensions peut altérer ou améliorer la participation. Contrairement à certains facteurs fonctionnels ou personnels, l'environnement offre une plus grande adaptabilité, ce qui en fait un sujet d'étude essentiel pour améliorer la participation. Le travail conceptuel de l'ICF Core Set pour les adultes avec PC a permis d'identifier les facteurs environnementaux qui sont essentiels pour améliorer la participation des adultes atteints de PC. Les travaux conceptuels de la CIF ont suggéré le rôle médiateur de l'environnement dans le lien entre les limitations fonctionnelles et les restrictions de participation. En d'autres termes, un état de santé altéré peut générer davantage de besoins environnementaux non satisfaits, qui à leur tour produisent des

restrictions de participation. Pour autant, cet effet n'a, à ce jour, pas été étudié dans la littérature internationale, d'où l'objectif de ce travail de thèse.

La réponse à ces objectifs a conduit à développer sur ce programme trois axes de travail pour lesquels nous avons préparé six papiers (cinq publiés et un en cours de publication), quatre en position de leader (1er et dernier auteurs) et deux en position de collaborateur :

Axe 1 : Participation à la vie sociale des jeunes adultes avec PC, avec :
- Un premier papier s'intéressant à l'emploi et aux études supérieures des jeunes adultes avec PC (publié en novembre 2023 dans le BMJ Public Health) ;
- Un papier s'intéressant aux différences de participation entre les jeunes adultes avec PC et la population générale (publié dans Disability and Health Journal en novembre 2023).

Axe 2 : Besoins de santé, accès aux soins et satisfaction vis-à-vis des soins, avec :
- Un papier s'intéressant au lien entre besoins environnementaux non satisfaits et besoins de santé non satisfaits (publié dans Frontiers in Rehabilitation Sciences en Février 2024) ;
- Un papier s'intéressant à la satisfaction vis-à-vis des soins de santé chez les jeunes adultes avec PC (publié dans Frontiers in Medicine en Janvier 2024).

Axe 3 : Rôle de l'environnement : mesure et lien avec la participation
- Un papier évaluant dans quelle mesure l'European Adult Environment Questionnaire (EAEQ), développé au cours de la 3ème vague de SPARCLE et mesurant l'environnement des jeunes adultes avec PC, couvre la CIF, et décrivant l'adéquation de l'environnement physique, social et attitudinal aux besoins spécifiques des jeunes adultes avec PC (publié en janvier 2024 dans Archives of Physical Medicine and Rehabilitation) ;

Méthodologie :

Nous avons utilisé les données de SPARCLE3, une étude observationnelle multicentrique européenne, conçue pour étudier l'impact de l'environnement sur la participation et la qualité de vie des jeunes adultes atteints de PC, et déterminer les facteurs prédictifs d'une vie de jeune adulte réussie dans les domaines de l'éducation, de la profession, de la santé et de la société. La conception de l'étude a été décrite en détails par ailleurs.[48]

Echantillon de l'étude :

La population éligible était composée de jeunes adultes, âgés de 22 à 27 ans au moment de la collecte des données en 2018-2020, avec un diagnostic de PC selon la définition du réseau Surveillance of Cerebral Palsy in Europe. Ils vivaient en France, Allemagne, Suède et Italie pour ceux qui avaient déjà participé à la cohorte SPARCLE en tant qu'enfants (âgés de 8 à 12 ans en 2004-2005, SPARCLE1) et/ou adolescents (âgés de 13 à 17 ans en 2009-2010, SPARCLE2). Un échantillon additionnel d'individus a été invité à participer dans toutes les régions, auquel s'est ajouté un nouveau centre au Portugal. L'échantillon total était de 310 sujets, dont 164 avaient participé aux vagues précédentes de la cohorte SPARCLE.

En France et en Allemagne, un groupe témoin de jeunes adultes de la même tranche d'âge a été recruté à l'aide d'une enquête en ligne. Les participants à l'enquête ont reçu des incitations de la part d'un panéliste qui a recruté des hommes et des femmes (dans une

proportion de 50%/50%) âgés de 19 à 29 ans et vivant dans l'un des deux pays participants (France : n = 2080 ; Allemagne : n = 1964).

Approbation éthique et consentement de participation :

Les autorisations éthiques et réglementaires ont été obtenues dans chaque pays. Tous les jeunes avec PC ou leurs représentants légaux ont donné leur consentement éclairé de participation ou leur non-opposition le cas échéant.

Recueil de données :

Des enquêteurs formés ont rendu visite aux jeunes adultes avec PC et ont mené des entretiens dans des conditions identiques dans chaque région. Dans la mesure du possible, les questionnaires ont été remplis par les intéressés eux-mêmes, avec l'aide du chercheur si nécessaire. Lorsque cela n'était pas possible, les questionnaires ont été complétés par une tierce personne (parent, assistant personnel ou partenaire) impliquée de manière significative dans la vie quotidienne de la personne avec PC et servant de proxy.

Les enquêteurs ont recueilli des informations standardisées sur les **déficiences et les comorbidités** : capacité de marche, motricité fine, déficience visuelle, capacité d'élocution et performance de communication. Les capacités intellectuelles ont été évaluées à l'inclusion à l'aide d'un test de QI formel ou d'un algorithme basé sur une série de questions posées à des proches [12]. Les jeunes adultes ont également fait état de leur fatigue au cours des deux dernières semaines et des crises d'épilepsie survenues au cours de l'année précédant l'entretien. Nous avons également recueilli des **facteurs contextuels personnels et familiaux** : taille de la population de la zone de résidence, mode de vie, niveau d'éducation personnel et parental le plus élevé et richesse perçue.

La **participation à la vie sociale** a été évaluée à l'aide du Questionnaire of Young People's Participation – Young Adults (QYPP-YA). Lors de l'entretien, il a été demandé aux jeunes adultes avec PC s'ils avaient un emploi, s'ils poursuivaient leurs études ou s'ils étaient au chômage, et recueilli des informations sur leur niveau d'éducation le plus élevé. Le questionnaire WHOQOL-Bref a été utilisé pour mesurer la **qualité de vie** (scores de 0 à 100, les scores les plus élevés indiquant une meilleure qualité de vie) dans quatre domaines : le bien-être physique, le bien-être psychologique, les relations sociales et l'environnement.

Les **besoins et la couverture en matière de soins de santé** ont été évalués à l'aide du questionnaire Youth Health Care, Satisfaction, Utilization and Needs (YHC-SUN). Un second module de 7 items a permis le recueil de la satisfaction vis-à-vis des soins de santé.

L'environnement physique, social et attitudinal a été appréhendé à l'aide de l'EAEQ, qui évalue 61 facteurs environnementaux (FE). Deux types d'informations étaient disponibles : le besoin du FE et sa couverture en cas de besoin, ou seulement sa couverture lorsque le besoin était considéré *a priori* comme commun à tous les individus. Les réponses ont été catégorisées comme "besoin environnemental non satisfait" lorsque la réponse "Besoin manifesté et non couvert" a été fournie, et "besoin environnemental satisfait" lorsque les réponses "Pas de besoin manifesté" ou "Besoin manifesté et couvert" ont été cochées, en fonction de l'item.

Analyses statistiques

Emploi et études supérieures : Pour cette analyse, nous avons restreint notre échantillon aux adultes avec PC, âgés de 22 à 27 ans, sans déficience intellectuelle modérée à profonde.

L'analyse a été effectuée séparément pour les statuts d'emploi et d'enseignement supérieur. Nous avons effectué des régressions logistiques inconditionnelles pour estimer les odds ratio (OR) et les intervalles de confiance à 95 % (IC 95 %) afin d'évaluer les associations avec les facteurs personnels, sociodémographiques et environnementaux.
Différences de participation avec la population générale : Nous avons comparé la participation des jeunes adultes avec PC à celle de leurs pairs de la population générale à l'aide d'un modèle expliquant les scores latents de participation par le statut de PC, ajusté pour les facteurs de confusion identifiés dans la population non atteinte de PC.
Accès aux soins : Nous avons effectué des régressions logistiques pour estimer les OR et leurs IC 95% qui mesurent les associations entre les besoins environnementaux non satisfaits dans chaque domaine (physique, social et attitudinal) et les besoins non satisfaits en physiothérapie, ergothérapie, orthophonie et accompagnement psychologique.
Satisfaction vis-à-vis des soins : Nous avons utilisé des analyses de corrélation pour explorer les associations entre la satisfaction à l'égard des soins de santé et les indicateurs respectifs liés à la disponibilité et à l'accessibilité des services de santé ainsi qu'à la sévérité des déficiences.
Mesure de l'inadéquation de l'environnement : Des FE pertinents pour les jeunes adultes atteints de PC ont été identifiés lors de focus groups en Angleterre et au Portugal. Les FE ont été mis en correspondance avec la classification environnementale de la CIF et la structure analytique de l'EAEQ a résulté de cette procédure de mise en relation. La validité du contenu a été évaluée à l'aide du bandwidth index (pourcentage de couverture de l'ICF Core Sets pour les adultes avec PC). Une analyse descriptive a été réalisée.

Résultats détaillés

Les résultats sont présentés sous la forme des résumés des articles publiés traduits en français (n=5), éventuellement complétés d'éléments qui nous ont paru importants, les PDF des publications étant fournis en annexes. Les résultats (non publiés) du dernier article juste soumis sont confidentiels. Le résumé en français est fourni.

Vidart d'Egurbide Bagazgoïtia N, Perret C, Himmelmann K, Thyen U, Ehlinger V, Duffaut C, Arnaud C, Sentenac M. **Employment and higher education in young adults with cerebral palsy: a cross-sectional analysis of the SPARCLE study.** BMJ Public Health 2023;1:e000141. https://doi.org/10.1136/bmjph-2023-000141

Contexte et objectifs

Pour les jeunes en situation de handicap, l'accès à l'enseignement supérieur et à l'emploi devrait conduire à une amélioration de l'estime de soi et du bien-être et, à long terme, à une plus grande inclusion dans la société. Nos objectifs étaient de décrire la situation des jeunes adultes avec PC en matière d'éducation et d'emploi, d'étudier les facteurs personnels et contextuels, y compris la scolarisation en milieu ordinaire durant l'enfance et l'adolescence, qui influencent le plus ces situations, et d'étudier dans quelle mesure l'emploi affecte la qualité de vie (QdV).

Méthodes

Nous avons utilisé les données de l'étude transversale SPARCLE3, recueillies en 2018-2020 dans cinq régions européennes. Les 227 participants éligibles étaient des adultes avec PC, âgés de 22 à 27 ans, sans déficience intellectuelle modérée à profonde. L'analyse a été effectuée séparément pour les statuts d'emploi et d'enseignement supérieur. Nous avons effectué des régressions logistiques inconditionnelles pour estimer les odd ratio (OR) et les intervalles de confiance à 95 % (IC 95 %) afin d'évaluer les associations avec les facteurs personnels, sociodémographiques et environnementaux. Nous avons testé la région, le sexe et l'âge comme facteurs de confusion potentiels. Parmi ceux-ci, nous avons retenu la région pour tous les modèles, ainsi que l'âge pour les modèles concernant le statut d'enseignement supérieur. Chaque variable a été analysée séparément après ajustement pour les facteurs de confusion potentiels identifiés précédemment. Dans tous les modèles, les OR ont été estimés en utilisant la vraisemblance pénalisée de Firth lorsque le nombre de cas était ≤5. En ce qui concerne les déficiences et les comorbidités, des modèles multivariés ont été utilisés pour contrôler les variables significatives dans des analyses séparées ($p<0,20$) et ces modèles ont été réduits en utilisant une méthode descendante étape par étape avec $p<0,05$ comme critère de signification statistique. Les déficiences et/ou comorbidités retenues dans les modèles multivariés précédents ont été ajoutées aux facteurs de confusion potentiels pour l'analyse des caractéristiques sociodémographiques et des facteurs environnementaux. Pour estimer l'impact de la scolarisation en milieu ordinaire pendant l'enfance et/ou l'adolescence, nous avons effectué des régressions logistiques inconditionnelles, ajustées sur les facteurs de confusion potentiels et les déficiences/comorbidités retenues précédemment, parmi le sous-échantillon d'individus ayant fourni cette information lors de leur participation antérieure à la cohorte SPARCLE. Enfin, des régressions linéaires ajustées pour la région et les déficiences/comorbidités ont été réalisées pour déterminer si le fait d'avoir un emploi était associé à une meilleure qualité de vie dans les domaines du bien-être physique, du bien-être psychologique, des relations sociales et de l'environnement.

Résultats

Nous avons montré que, dans l'ensemble, 45,4 % des jeunes adultes atteints de PC et ayant un QI ≥50 ne suivaient pas d'études supérieures et n'avaient pas d'emploi. Parmi ceux qui avaient un emploi (35,2 %), plus de 4 sur 5 déclaraient être rémunérés, se voir confier des tâches adaptées à leurs capacités ou être satisfaits de leur capacité de travail. La probabilité d'avoir un emploi était significativement réduite (de plus de 75 %) pour les jeunes souffrant de graves limitations de la motricité globale ou de graves difficultés de communication, par rapport aux participants moins gravement handicapés. La probabilité d'obtenir un diplôme de l'enseignement supérieur était réduite d'un facteur de 0,19 pour les jeunes souffrant de déficiences motrices graves et de 0,02 pour ceux dont la parole est imprécise ou incompréhensible. Le fait d'être diplômé de l'enseignement supérieur et d'avoir fréquenté une école ordinaire pendant l'enfance, ou d'avoir poursuivi une scolarité ordinaire jusqu'à l'adolescence, s'est avéré être un puissant levier pour l'accès à l'emploi (les chances d'être employé ont été multipliées par 12 et 16, respectivement). À l'exception de l'accessibilité à un parking en cas de besoin, aucun des facteurs environnementaux étudiés n'a influencé de manière significative l'emploi ou le statut d'enseignement supérieur, après ajustement pour les déficiences. Les jeunes adultes ayant un emploi ont fait état d'un bien-être physique et psychologique significativement plus élevé que ceux qui n'en avaient pas.

Discussion

Cette étude transversale apporte un nouvel éclairage sur les barrières et les leviers d'accès à l'emploi ou à l'enseignement supérieur chez les jeunes adultes avec PC. Nous avons montré que les déficiences sévères de la motricité et de la communication sont les deux principaux facteurs qui limitent l'emploi ou l'achèvement de l'enseignement supérieur. Si nous complétons les données existantes sur le rôle de l'enseignement supérieur dans l'accès à l'emploi, nous sommes les premiers à étudier et à observer que le fait d'avoir fréquenté une école ordinaire pendant l'enfance ou d'avoir poursuivi une scolarité ordinaire jusqu'à l'adolescence est un puissant levier pour l'accès à l'emploi. A notre connaissance, cette étude est la première à examiner les associations entre l'environnement et l'emploi et l'enseignement supérieur, et à rapporter le rôle positif de l'accessibilité à un parking en cas de besoin sur l'emploi ou le statut dans l'enseignement supérieur. Enfin, nous sommes les premiers à rapporter l'impact positif de l'emploi sur la qualité de vie physique et psychologique de jeunes adultes atteints de paralysie cérébrale. De façon générale, les études portant sur les jeunes adultes avec PC montrent que leur accès à l'emploi peut encore être améliorée. Nos résultats suggèrent que l'inclusion des jeunes handicapés dans la société dès leur plus jeune âge et leur maintien autant que possible dans cette position favorisent leur accès à l'enseignement supérieur et à l'emploi à l'âge adulte. Compte tenu de l'impact positif de l'emploi sur leur qualité de vie, cela encourage la mise en œuvre de politiques d'inclusion dès le plus jeune âge.

Guyard A, Fauconnier J, Muehlan H, Cytera C, Markwart H, Himmelmann K, Schmidt S, Duffaut C, Arnaud C, Thyen U. **Differences in participation between young adults with cerebral palsy and their peers: A cross-sectional multicentre European study**. Disabil Health J 2024;17(2):101554. https://doi.org/10.1016/j.dhjo.2023.101554

Contexte

On sait que les enfants et les adolescents handicapés participent moins à la plupart des domaines de la vie que leurs pairs non handicapés.

Objectifs

(1) Estimer les différences de participation entre les jeunes adultes atteints d'infirmité motrice cérébrale (IMC) et leurs pairs non handicapés ; (2) tester le rôle médiateur des difficultés financières et du statut d'étudiant ; (3) tester le rôle modérateur des facteurs personnels sur les différences de participation ; et (4) tester le rôle modérateur de la déficience.

Méthodes

Une étude transversale a été menée auprès de jeunes adultes [19-28 ans] avec PC (n=228) et de pairs non handicapés (n=2861) en France, en Allemagne et en Suède. La participation a été évaluée à l'aide du questionnaire de participation des jeunes adapté aux jeunes adultes (QYPP-YA). Les différences dans cinq domaines de participation ont été estimées à l'aide d'une modélisation par équations structurelles avec la méthode WLSMV et des intervalles de confiance bootstrap corrigés des biais.

Résultats

Les jeunes adultes atteints de PC ont montré une participation plus faible que les autres dans tous les domaines, la différence la plus importante se situant dans le domaine des "relations intimes" (β = 1,71 IC 95%[1,46 ; 1,95]). Le statut d'étudiant a joué un rôle médiateur dans la différence au niveau des "relations intimes", des "relations interpersonnelles" et de l'"indépendance". Les femmes ont montré des différences plus importantes que les hommes en ce qui concerne l'"indépendance". Les déficiences ont modéré les différences de participation. Les jeunes adultes les moins gravement handicapés ne présentaient aucune différence avec leurs pairs non PC en ce qui concerne les "relations interpersonnelles", la "vie sociale" et l'"indépendance", mais ils prenaient plus souvent des décisions autonomes au quotidien que leurs pairs.

Conclusions

Les jeunes adultes avec PC n'ont pas les mêmes possibilités d'atteindre le niveau de participation des personnes non atteintes de PC du même âge. La poursuite de l'éducation pourrait contribuer à réduire les différences de participation dans les domaines des "relations interpersonnelles" et de l'"indépendance".

Rioual J, Perret C, Arnaud C, Vidart d'Egurbide Bagazgoïtia N. **Unmet environmental needs and unmet healthcare needs in a population of young adult with cerebral palsy: what the SPARCLE study tells us.** Front Rehabil Sci 2024 ; 2:5:1294999.
https://doi.org/10.3389/fresc.2024.1294999

Contexte et objectifs

L'optimisation des soins aux jeunes adultes atteints de paralysie cérébrale est cruciale pour leur bien-être physique et psychologique. L'inadéquation de l'environnement proximal peut jouer un rôle dans la prestation des services de santé. L'objectif de cette étude est d'explorer l'association entre les besoins environnementaux non satisfaits dans les domaines physique, social et attitudinal et les besoins de soins de santé non satisfaits dans le cadre de quatre interventions : physiothérapie, ergothérapie, orthophonie et conseils psychologiques.

Méthodes

Pour cela, 310 jeunes adultes avec PC ont été recrutés dans le cadre de l'étude transversale multicentrique européenne SPARCLE3. Les besoins et la couverture en matière de soins de santé ont été évalués à l'aide du questionnaire Youth Health Care, Satisfaction, Utilization and Needs (YHC-SUN). Les informations concernant l'environnement physique, social et attitudinal ont été recueillies à l'aide de l'European Adult Environment Questionnaire (EAEQ), un questionnaire élaboré dans le cadre de SPARCLE3, qui évalue l'adéquation de 61 facteurs environnementaux (FE). Deux types d'informations étaient disponibles : le besoin du FE et sa couverture en cas de besoin, ou seulement sa couverture lorsque le besoin était considéré a priori comme commun à tous les individus. Les réponses ont été catégorisées comme "besoin environnemental non satisfait" lorsque la réponse "Besoin manifesté et non couvert" a été fournie, et "besoin environnemental satisfait" lorsque les réponses "Pas de besoin manifesté" ou "Besoin manifesté et couvert" ont été cochées, en fonction de l'item. Dans chaque domaine de l'environnement, les éléments relatifs à l'accès aux soins ont été

sélectionnés a priori. Quatre sous-groupes ont été identifiés en fonction des besoins en physiothérapie, ergothérapie, orthophonie ou accompagnement psychologique qu'ils ont déclarés. Nous avons d'abord décrit la répartition des déficiences, des comorbidités et des facteurs contextuels dans l'ensemble de l'échantillon et dans les sous-groupes. La proportion de jeunes adultes ayant déclaré des besoins environnementaux non satisfaits a été estimée dans les mêmes sous-groupes. En outre, pour chaque domaine environnemental, nous avons représenté graphiquement la proportion d'individus ayant des besoins de santé non satisfaits par rapport au nombre de besoins environnementaux non satisfaits afin de déterminer des catégories, en considérant les individus n'ayant aucun besoin non satisfait comme la classe de référence, et un minimum de cinq individus dans chaque catégorie. Ensuite, des analyses distinctes ont été effectuées pour les sous-groupes de physiothérapie, d'ergothérapie, d'orthophonie et d'accompagnement psychologique afin d'évaluer le rôle des facteurs environnementaux sur la satisfaction des besoins en matière de soins de santé. Des comparaisons bivariées ont été effectuées entre la proportion de personnes ayant des besoins de santé non satisfaits et les caractéristiques sociodémographiques et les déficiences. Nous avons ensuite effectué des régressions logistiques pour estimer les OR et leurs IC 95% qui mesurent les associations entre les besoins environnementaux non satisfaits dans chaque domaine et les besoins non satisfaits en physiothérapie, ergothérapie, orthophonie et accompagnement psychologique. Tous les modèles ont été ajustés en fonction du pays, en raison de la diversité du recrutement et des politiques en faveur des personnes handicapées dans les différents pays, et du sexe. Le modèle 1 a été systématiquement ajusté pour le GMFCS et le modèle 2 pour la taille de l'unité de résidence et le mode de vie. Afin d'identifier d'éventuels facteurs de confusion supplémentaires, deux sélections successives par étapes ont été effectuées : la première a ajouté des variables cliniques (déficience intellectuelle, communication, intensité et fréquence de la douleur) aux modèles 1, tandis que la seconde a inclus des variables sociodémographiques (éducation, niveau de revenus et niveau d'éducation le plus élevé des parents) en plus des modèles 2, dans le but de réduire au minimum le nombre de variables introduites dans les modèles. Des modèles multivariés ont été utilisés pour contrôler les variables significatives dans des analyses séparées ($p<0,20$) et ces modèles ont été réduits en utilisant une méthode descendante étape par étape avec $p<0,05$ comme critère de signification statistique. Les participants ayant des données manquantes pour une ou plusieurs variables dans les différents modèles étaient peu nombreux et ont été exclus des analyses.

Résultats

Notre étude a montré que le besoin de soins le plus courant était la physiothérapie, qui a été signalée par plus de quatre jeunes adultes atteints de PC sur cinq. Parmi ceux qui ont exprimé un besoin de soins, la proportion de ceux dont le besoin n'a pas été satisfait varie en fonction du type de soins requis : 20,8 % à 48,5 % pour la rééducation, et 40,3 % pour l'accompagnement psychologique. Nous avons trouvé une association entre un environnement inadapté aux besoins spécifiques des jeunes atteints de PC et leurs besoins de soins. Plus précisément, l'accumulation de besoins non satisfaits dans l'environnement social, explorant le soutien de l'assistant personnel, de la famille et des amis, du personnel de santé et des collègues, et des étrangers, était associée à des besoins non satisfaits dans tous les domaines de santé explorés, même en tenant compte de la gravité des déficiences et des caractéristiques sociodémographiques des individus. L'absence d'attitudes de soutien multipliait par plus de trois le risque de signaler également un besoin non satisfait

d'orthophonie et de physiothérapie, uniquement chez les personnes dont la fonction motrice globale était la plus gravement altérée dans ce dernier cas. Enfin, notre étude n'a montré aucune association entre les besoins non satisfaits dans l'environnement physique et les besoins non satisfaits en matière de soins de santé.

Discussion

À notre connaissance, aucune publication n'a spécifiquement évalué la relation entre les besoins de santé non satisfaits des jeunes adultes atteints de PC et l'adéquation de leur environnement à leurs besoins spécifiques. Nos résultats soulignent l'importance de l'environnement social et du soutien. À cet âge, une plus grande indépendance et émancipation, notamment vis-à-vis des parents, pourrait expliquer en partie pourquoi les jeunes adultes ont des besoins de santé non satisfaits plus importants que les enfants. On peut émettre l'hypothèse que l'absence d'association entre l'environnement physique et les besoins de santé non satisfaits est due au fait que l'environnement physique est souvent compensé par le soutien social et l'aide de la famille et des amis. Ainsi, un jeune adulte pourrait se déplacer facilement s'il est accompagné, même dans un environnement moins adapté, alors qu'un individu moins soutenu aurait plus de difficultés même dans un environnement physique mieux adapté. Il est également concevable que cette différence soit liée aux déficiences cognitives, qui posent souvent plus de défis à la mobilité indépendante que les déficiences motrices, pour lesquelles des adaptations sont généralement possibles. Nos résultats suggèrent que plus les besoins non satisfaits dans l'environnement social sont importants, plus les besoins non satisfaits en matière de soins de santé pour l'ergothérapie, l'orthophonie et l'accompagnement psychologique sont importants. Cependant, en raison du petit nombre de participants présentant de multiples besoins non satisfaits dans leur environnement social, ces résultats doivent être interprétés avec prudence. Nos résultats indiquent que le soutien attitudinal est associé à des besoins de soins de santé non satisfaits en orthophonie, qui concerne la plupart des personnes atteintes de déficiences motrices et cognitives graves, et en physiothérapie pour les personnes atteintes de déficiences motrices graves. Cela suggère que ce soutien est particulièrement crucial pour garantir l'accès aux soins de santé pour ces thérapies chez les jeunes adultes gravement handicapés atteints de PC. Nous n'avons pas trouvé cette association chez les personnes qui avaient besoin d'ergothérapie ou de accompagnements psychologiques.

En conclusion, notre étude a montré que l'adéquation de l'environnement, tant social qu'attitudinal, peut avoir un impact sur les besoins de santé non satisfaits dans différents domaines thérapeutiques chez les jeunes adultes atteints de PC. Elle apporte un éclairage précieux sur les facteurs influençant les besoins de santé non satisfaits dans cette population. Toutefois, des recherches supplémentaires sont nécessaires pour mieux comprendre et délimiter ces deux domaines environnementaux et pour explorer plus en profondeur leur relation avec l'accès aux soins de santé.

Muehlan H, Alvarelhao J, Arnaud C, Cytera C, Fauconnier J, Himmelmann K, Marcelli M, Markwart H, Rapp M, Schmidt S, et al. **Satisfaction with health care services in young people with cerebral palsy in the transition period: results from a European multicenter study.** Front Med 2024; 11:1306504. https://doi.org/10.3389/fmed.2024.1306504

Contexte et objectifs

Les jeunes souffrant de maladies chroniques et de handicaps comptent sur le système de santé pour maintenir le meilleur état de santé possible. La délivrance et l'utilisation appropriées des services et soins de santé sont essentielles pour améliorer leur autonomie, leur efficacité personnelle et leurs résultats en matière d'emploi. La question de recherche de notre étude vise à déterminer si le manque de disponibilité et d'accessibilité des services de santé en général, identifiés par les besoins non satisfaits en matière de soins de santé, est associé à l'insatisfaction à l'égard des soins de santé.

Méthodes

Dans le cadre d'une étude observationnelle multicentrique européenne, 357 jeunes adultes avec PC et âgés de 19 à 28 ans ont été inclus. Nous avons évalué les besoins en soins, l'utilisation des services de santé et la satisfaction à l'égard des soins de santé à l'aide de la version abrégée du questionnaire YHC-SUN-SF, des variables environnementales et sociales (EAEQ) ainsi que des indicateurs de la gravité de l'état de santé et des limitations fonctionnelles (par exemple, GMFCS) de ces participants sur la base d'une autoévaluation, éventuellement avec assistance, ou par procuration. Nous avons utilisé des analyses de corrélation pour explorer les associations entre la satisfaction à l'égard des soins de santé et les indicateurs respectifs liés à la disponibilité et à l'accessibilité des services de santé ainsi qu'à la sévérité de la maladie. En outre, nous avons inclus des valeurs de référence pour la satisfaction à l'égard des soins de santé de jeunes adultes souffrant de diverses maladies chroniques, évaluées dans le cadre d'enquêtes basées sur la population de certains des pays européens inclus dans l'étude.

Résultats

Nous avons identifié plusieurs besoins non satisfaits en matière de soins de santé, en particulier pour des services largement utilisés et établis tels que la kinésithérapie. La satisfaction à l'égard des soins de santé (scores généraux et sous-échelles du YHC-SUN-SF) était modérée à élevée et presque systématiquement meilleure pour l'échantillon de jeunes adultes avec PC par rapport aux valeurs de référence pour les jeunes adultes souffrant de diverses maladies chroniques évaluées dans le cadre d'enquêtes auprès de la population générale. Les coefficients de corrélation entre la satisfaction à l'égard des soins de santé, l'utilisation des services et les besoins non satisfaits en matière de soins de santé étaient faibles.

Conclusion

Les rapports des jeunes adultes avec PC sur les besoins non satisfaits en matière de soins de santé présentent une grande variabilité, mais montrent des déficits substantiels dans certains aspects. Cela ne semble pas avoir d'impact sur la satisfaction des soins de santé que ces patients reçoivent. Nous concluons qu'il s'agit de deux concepts différents et d'indicateurs quelque peu indépendants pour évaluer la qualité des soins de santé. Les

cliniciens et autres praticiens devraient tenir compte de cette distinction lorsqu'ils évaluent les besoins des patients dans leur pratique quotidienne.

Perret C, Alvarelhão J, Pennington L, Ehlinger V, Duffaut C, Arnaud C, Vidart d'Egurbide Bagazgoïtia N. **Assessing the Adequacy of the Physical, Social and Attitudinal Environment to the Specific Needs of Young Adults with Cerebral Palsy: Development and Description of the European Adult Environment Questionnaire.** Arch Phys Med Rehabil 2024; 11:S0003-9993(23)00693-7. https://doi.org/10.1016/j.apmr.2023.11.012

Contexte

La mesure de l'environnement des jeunes avec handicaps dans le cadre du modèle conceptuel de la CIF pose de nombreuses questions. Dans le cadre de l'étude européenne SPARCLE3, nous avons développé un questionnaire de 61 items pour mesurer l'adéquation de l'environnement aux besoins individuels des jeunes adultes avec PC. Les facteurs environnementaux pertinents pour les jeunes adultes avec PC ont été identifiés lors de groupes de discussion en Angleterre et au Portugal.

Objectifs

- Présenter l'élaboration du questionnaire européen sur l'environnement (European Adult Environmental Questionnaire EAEQ)
- Evaluer dans quelle mesure il couvre la classification environnementale de la CIF
- Décrire l'adéquation de l'environnement physique, social et attitudinal aux besoins spécifiques des jeunes adultes avec PC.

Méthodes

Etude transversale multicentrique européenne (France, Allemagne, Italie, Portugal, Suède), incluant de jeunes adultes avec PC (N=357), avec des profils de gravité variés, âgés de 19 à 28 ans au moment de l'entretien (2018-20). Nous avons mesuré les besoins non satisfaits de l'environnement physique, social et attitudinal.

Résultats

Les facteurs environnementaux (FE) pertinents pour les jeunes adultes atteints de PC, identifiés lors de groupes de discussion en Angleterre et au Portugal, ont été mis en correspondance avec la classification environnementale de la CIF et la structure analytique de l'EAEQ a résulté de cette procédure de liaison. Le questionnaire, comprenait 61 items au total, liés à 31 catégories de la classification environnementale de la CIF, et couvrait 4 de ses 5 chapitres (« produits et technologies » (19 items), « soutien et relations » (8 items), « attitudes » (6 items), « systèmes et politiques de service » (22 items) et « comprendre et être compris » (6 items)). La validité du contenu, évaluée à l'aide de l'indice de largeur de bande (pourcentage de couverture des ensembles fondamentaux de la CIF pour les adultes avec PC), était satisfaisante (79,3 %).

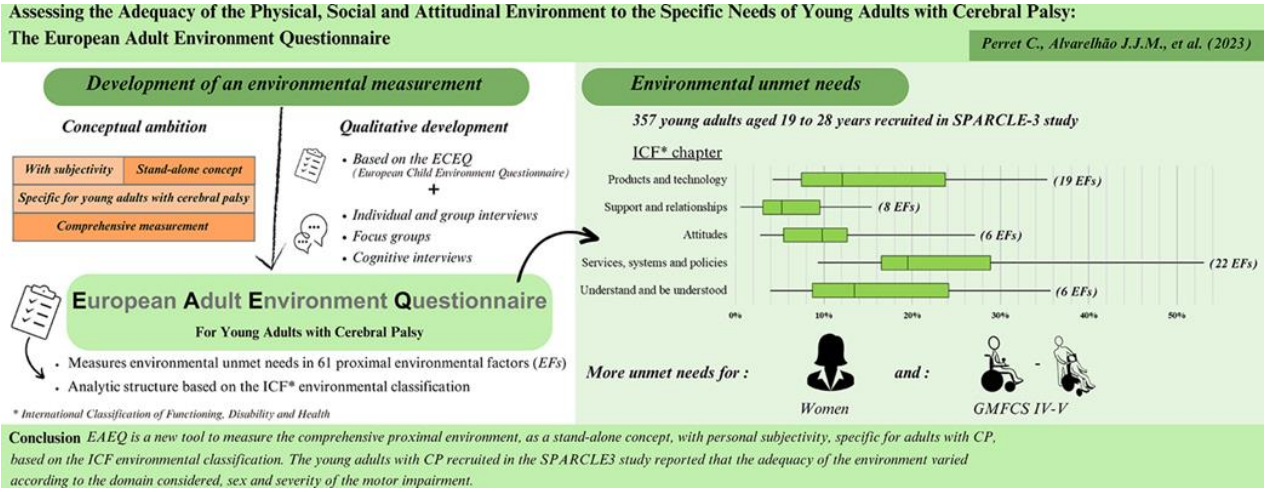
Lors de notre exploration descriptive, nous avons montré que la proportion de besoins environnementaux non satisfaits varie selon les chapitres. De façon plutôt positive, nous avons observé de faibles proportions de besoins non satisfaits relatifs aux « soutiens et relations » et aux « attitudes » (<10%) qui concernent plutôt des données proximales. Au

contraire, ceux liés aux « systèmes et politiques de service » et « produits et technologie » correspondent moins bien aux besoins (10-20% de besoins non satisfaits). De tous les services explorés, ceux liés à la communication et à l'information correspondaient très mal aux besoins. Il a déjà été démontré que la fourniture d'informations appropriées et l'accès aux technologies de communication améliorent la vie des personnes handicapées et favorisent une véritable inclusion dans la société. [47] Enfin, de façon générale, on retrouvait plus de besoins environnementaux non satisfaits chez les femmes et les jeunes présentant une atteinte sévère des fonctions motrices globales (GMFCS IV-V).

Conclusion

Ce questionnaire EAEQ permet de collecter les FE utiles aux personnes avec PC et d'analyser si leur disponibilité, leur modification ou leur adaptation pourrait améliorer la réalisation des activités quotidiennes, la participation et la qualité de vie. Malgré le grand nombre d'items, qui pourrait rendre le questionnaire fastidieux à remplir, nous avons observé un taux de réponse élevé pour tous les items (plus de 96%), ce qui souligne son acceptabilité. Cela suggère la possibilité d'une utilisation généralisée dans la pratique clinique. En mesurant systématiquement un large éventail de FE, les professionnels de la santé pourraient se faire une idée précise de l'étendue des besoins de leurs patients et les aider à apporter les compensations nécessaires. L'analyse des différences géographiques ou temporelles de fréquence de participation ou de niveau de qualité de vie, couplée à une vision globale des besoins environnementaux non satisfaits, pourrait fournir aux pouvoirs publics les éléments d'une politique d'accessibilité et d'intégration des personnes handicapées dans la société. Enfin, la mesure indépendante de l'environnement ouvre de nouvelles voies pour l'étude des associations entre l'environnement et une série d'indicateurs de résultats rapportés par les patients (Patient Reported Outcomes Measures), insuffisamment connus et utilisés en France, et ceci de manière complémentaire à ceux rapportés par les professionnels, comme recommandé par la Haute Autorité de Santé.

Résumé graphique (en anglais)



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Annexes

Copie des publications

BMJ Public Health

Employment and higher education in young adults with cerebral palsy: a cross-sectional analysis of the SPARCLE study

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ABSTRACT

Introduction For young people with disabilities, access to higher education and employment should lead to improved personal self-esteem and well-being and, in the long run, to increased inclusion in society. Our aims were to describe the education and employment status of young adults with cerebral palsy (CP), to investigate the personal and contextual factors, including prior mainstream education, that most influence these statuses, and to study to what extent employment affects the quality of life (QoL).

Methods We used data from the SPARCLE3 cross-sectional study, collected in 2018–2020 in five European regions. Eligible participants were adults with CP, 22–27 years, without moderate to profound intellectual disability. Outcomes were education and employment statuses. Unconditional logistic regressions were performed to test the association with impairments, comorbidities, personal and family characteristics and environmental factors. QoL scores (WHOQOL-bref score 0–100) were compared using linear regressions.

Results Of the 227 participants, 21.6% had a tertiary degree, 35.2% were employed. The likelihood of being employed or of having a tertiary degree was reduced by more than 75% for those with more severe gross motor limitations or communication/speech difficulties. Those with a tertiary degree were more likely to be employed (OR 9.37 (95% CI 2.87 to 30.64)) while accessible car parking was the only associated environmental factor (OR 2.92 (95% CI 1.19 to 7.18)). Prior mainstream schooling increased the odds of being employed 16-fold. Individuals who were employed reported an 8-point increase in the physical and psychological well-being domains of QoL compared with those who were unemployed.

Conclusions The employment situation of young adults with CP can still be improved, but our findings encourage the implementation of inclusive policies from an early age.

INTRODUCTION

Throughout their lives, individuals with disabilities face numerous barriers, limiting their involvement in life situations and social roles.[1] In recent decades, responses to these restrictions have evolved alongside the conceptualisation of disability. Historically, this concept was based on a medical and individual model, considering disability and its associated limitations as the result of impairments (physical, sensory, psychic and mental), and providing for segregated solutions such as residential institutions and special schools.[2] Since the 1990s, disabled peoples' movements[3 4] and researchers[5] have shifted the conceptual definition of disability from a 'medical model'to a'social model'. In the latter, disability is not the result of the individual's incapacity but rather of inadequacy of the environment for their disability, thus challenging society to accommodate impairment. As disability should be viewed as neither purely medical nor purely social, the International Classification of Functioning, Disability and Health (ICF) proposed in 2001a balanced multidimensional concept that sees disability as a dynamic interaction between 'body functions and structures'and 'personal and environmental contextual factors' that results in reduced activities of daily living and limited participation in social activities.[6 7] Disability is thus related to the inadequacy of the physical, social and attitudinal environment to the complex needs of people with reduced functioning. Similarly to their counterparts in the general population to whom the ICF model also refers, people with disabilities may report varying levels of activity and participation, but these are increasingly reduced with increasing severity of impairment.[8–12] Identifying and addressing societal barriers in the environment, and focusing on community and educational inclusion together with more interactive medical approaches, can help improve participation.[13]

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WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ We found three articles on employment or higher education in adults with cerebral palsy. Studies have shown lower employment rates in individuals with severe intellectual and physical disability, epilepsy, fatigue and low educational level, while factors influencing access to higher education remain to be investigated. No previous studies have examined the role of environmental factors and mainstream schooling on access to employment or higher education, or the extent to which being employed can increase quality of life.

WHAT THIS STUDY ADDS

⇒ This cross-sectional study sheds new light on the barriers and levers for accessing employment or higher education in young adults with cerebral palsy. We showed that severe impairments of gross motor function and communication are the two main factors that limit employment or completion of higher education. While we add to existing evidence for the role of higher education in access to employment, we are the first to investigate and observe that having attended a mainstream school during childhood or continued mainstream education until adolescence is a powerful lever for access to employment. To our knowledge, this study is the first to examine the associations between environment and employment and higher education, and to report the positive role of accessibility to car parking when needed on employment or higher education status. Lastly, we are the first to report the positive impact of employment on the physical and psychological quality of life of young adults with cerebral palsy.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Studies focusing on young adults with cerebral palsy demonstrate that their employment situation can still be improved. Our findings suggest that including young people with disabilities in society from an early age and keeping them there as much as possible promotes their access to higher education and employment in young adulthood. Given the positive impact of employment on their quality of life, this encourages the implementation of inclusive policies from an early age.

The literature reports that effective inclusion in society of young people with disabilities generates opportunities for personal development and improves well-being, notably for individuals with cerebral palsy (CP).[14] CP is the most frequent childhood-onset physical disability. It results in permanent disorders of movement, posture and motor function that may be associated with sensory, perceptual, cognitive, communication and behavioural disorders, epilepsy and secondary musculoskeletal problems.[15] Previous research mainly focused on children reporting significant differences between countries in public policies towards disability and their implementation, support and care services, education[16] or accessibility, which provided a better understanding of the impact of an unsupportive environment on engagement in social roles. However, knowledge on participation in adulthood remains scarce, although it is now estimated that a large majority of children with CP will experience this period in their lives.[17 18] Two normative social roles for young adults are enrolment in higher education and/or getting a worthwhile job, both areas where those with disabilities may experience restrictions or barriers. Reported rates of employment in adults with CP range from 17% to 53%, markedly lower than that of the general population in Western countries.[19–25] Factors influencing the employment rate of young adults with CP include severe intellectual and physical disability, epilepsy, fatigue and low educational level,[22 24 26] while factors influencing access to higher education remain to be investigated. Although research has yielded limited evidence, we may assume that experiences in inclusive settings from an early age, particularly mainstream schooling, bring personal satisfaction with life, enhance social roles and increase post-secondary education choice and employment aspirations.

We aimed to describe the higher education and employment status of young adults with CP, to investigate the role of personal, sociodemographic and environmental factors, to determine whether mainstream education in childhood and/or adolescence had a significant impact and to study to what extent being employed was associated with increased quality of life (QoL).

MATERIALS AND METHODS

Study design, data source and study population

We used data from the SPARCLE3 study, a multicentre European observational population-based study designed to investigate the impact of the environment on participation and QoL of young adults with CP, and to determine predictors of successful young adulthood in educational, professional, health and social fields. The study design has been described elsewhere.[27] Briefly, the eligible population consisted of young adults, aged 22–27 years at the time of data collection in 2018–2020, with a diagnosis of CP according to the definition of the Surveillance of Cerebral Palsy in Europe network.[28] They lived in France, Germany, Sweden and Italy for those who previously participated in the SPARCLE cohort as children (aged 8–12 years in 2004–2005, SPARCLE1)[29] and/or adolescents (aged 13–17 years in 2009–2010, SPARCLE2),[30] and in Portugal for those who had not previously participated. Additional individuals were invited to participate in all regions, resulting in a total sample of 310 participants, 164 of whom had participated in previous waves of the SPARCLE cohort. For this analysis, the sample was restricted to those without moderate to profound intellectual impairment (IQ ≥50) at inclusion and who had the capacity to work (figure 1).

Patient and public involvement

Patients were not involved in the design and the conduct of this study. However, young adults with CP were involved through focus group discussions and interviews in identifying outcomes relevant to the development of new environmental and participation measurement instruments (European Adult Environment Questionnaire (EAEQ) and QYPP-YA, respectively) used in the SPARCLE3 study.

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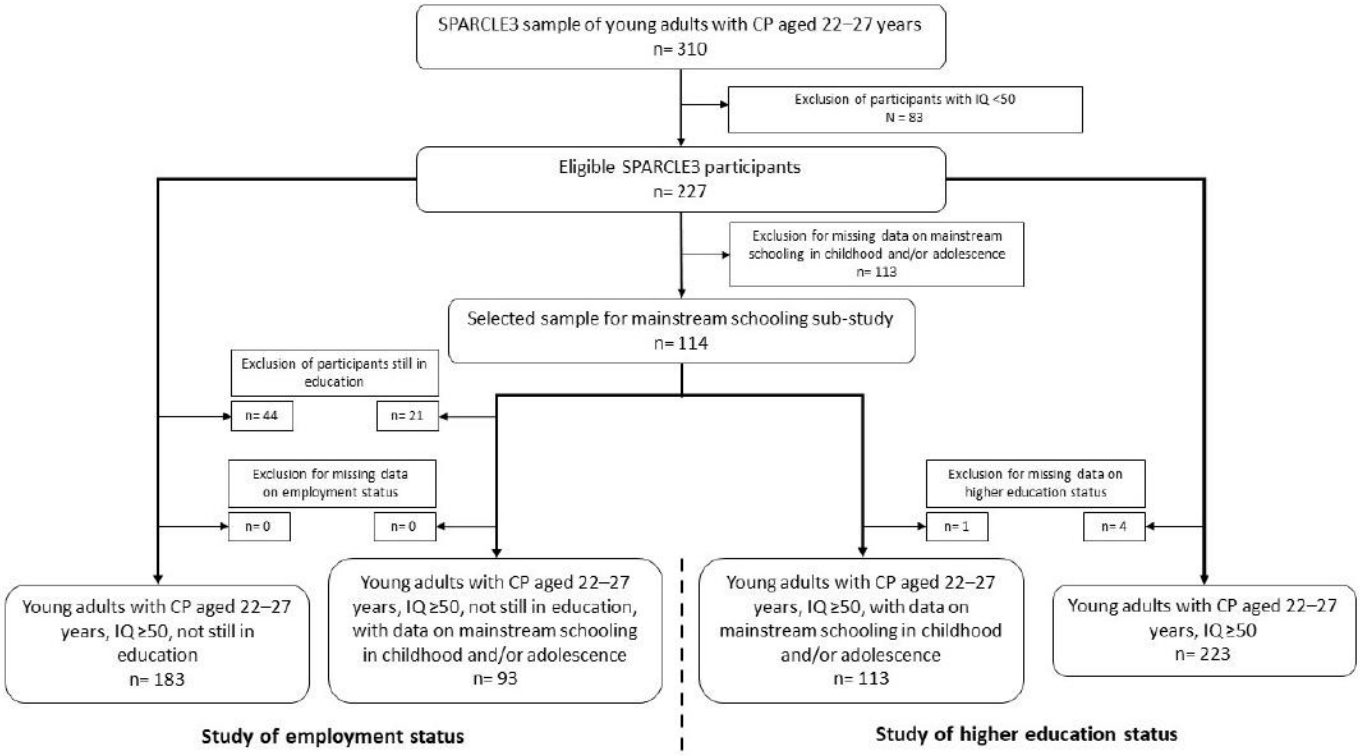

Figure 1 Description of the selection of samples used for the analyses—SPARCLE3—France, Germany, Italy, Portugal and Sweden, 2018–2020. CP, cerebral palsy.

Ethics statement

We sought the relevant ethical and regulatory authorisations in each country. All young people with CP or their legal representatives gave written informed consent to participate, or non-opposition where appropriate.

Procedures and data collected

Trained research associates visited young adults with CP and conducted interviews under identical conditions in each region. Whenever possible, the questionnaires were self-completed, with the researcher's assistance when needed. When self-reports were not possible, even with help, proxy reports were obtained from an individual (parent, personal assistant or partner) significantly involved in the daily life of the person with CP.

At the interview, young adults with CP were asked if they were employed, still in education or unemployed. Those who had a job stated whether they were paid, whether they were working full-time or part-time, if tasks were appropriate to their ability and whether they were satisfied with their work capacity. We collected information about their highest education level, thereafter categorised as secondary education completed or lower/tertiary education completed. Interviewers gathered standardised information about impairments and comorbidities using schemes and/or decision trees: walking ability (using the Gross Motor Function Classification System (GMFCS),[31] fine motor skills (Bimanual Fine Motor Function (BFMF),[32] visual impairment (Short Set of Questions on Disability, Washington Group, difficulty or inability to see, even if wearing glasses, yes/no),[33] speaking ability (Viking Speech Scale, VSS)[34] and communication performance (Functional Communication Classification System, FCCS).[35] We assessed intellectual ability at inclusion with formal IQ testing or using an algorithm based on a set of questions to proxies.[12] The IQ was categorised as 50–69/≥70. Young adults also reported their fatigue over the past 2 weeks (not at all/yes, at least several times) and seizures in the year predating interview (yes/no).

The following contextual factors were collected: population size of their area of residence (>200 000/3000–200 000/<3000 inhabitants), lifestyle (living independently, with parents, in care facilities, other) and parental highest education level (tertiary degree yes/no). We extracted nine environmental items covering transport, adapted equipment and support from the EAEQ, assessing the availability of needed physical, social and attitudinal environmental items relevant to young adults with CP. It was adapted from a similar instrument validated for children and adolescents,[36] and included some new items (eg, communication technologies) relevant to young adults.

The WHOQOL-Bref questionnaire[37] was used to measure QoL (scores of 0–100, higher scores indicating higher QoL) in four domains: physical well-being, psychological well-being, social relationships and environment.

For the subsample of individuals who had previously participated in the SPARCLE cohort as children and/or adolescents, we also had information about mainstream schooling at these targeted periods.

Statistical analysis

Analysis was carried out separately for employment and higher education statuses. We performed unconditional

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logistic regressions (SAS V.9.4, SAS Institute, Cary, North Carolina, USA) to estimate ORs and 95% CI to assess the associations with personal, sociodemographic and environmental factors. We tested region, sex and age as potential confounders. Of these, we retained region for all models, and also age for models for higher education status. Each variable was analysed separately after adjustment for the potential confounders previously identified. In all models, ORs were estimated using Firth's penalised likelihood when the number of cases was ≤5. Regarding impairments and comorbidities, multivariate models were used to control for significant variables in separate analyses (p<0.20) and these models were reduced using a descending step-by-step method with p<0.05 as a criterion for statistical significance. The impairments and/or comorbidities retained in previous multivariate models were added to potential confounders for analysis of sociodemographic characteristics and environmental factors.

To estimate the impact of mainstream schooling during childhood and/or adolescence, we performed unconditional logistic regressions, adjusted for potential confounders and impairments/comorbidities previously retained, among the subsample of individuals who provided this information during their previous participation in the SPARCLE cohort.

Lastly, linear regressions adjusted for region and impairments/comorbidities were performed to explore whether being employed was associated with better QoL in physical well-being, psychological well-being, social relationships and environment domains.

Role of funding source

The funders had no role in study design, data collection, data analysis, data interpretation or writing of the publication.

RESULTS

Our cross-sectional sample included 227 young adults with CP with IQ ≥50 at inclusion. Their mean age was 24.3 years (SD 1.6 years) and male-to-female ratio was 1:3.

A large majority (78.4%) had not completed university studies. At the interview, 19.4% were still in education, 35.2% were employed and 45.4% were unemployed. Young adults who were employed mostly reported having paid work (88.8% of workers), working full-time (60.0%), given always or most of the time tasks appropriate to their ability (87.5%) and being satisfied or very satisfied with their work capacity (83.8%) (table 1).

Table 1 Sociodemographic characteristics of young adults with CP without moderate to profound intellectual impairment (n=227)— SPARCLE3—France, Germany, Italy, Portugal and Sweden, 2018–2020

	n	%
Country		
France	65	28.6
Germany	64	28.2
Italy	14	6.2
Portugal	65	28.6
Sweden	19	8.4
Sex		
Male	127	55.9
Female	100	44.1
Age (years)		
Mean (SD)	24.3	1.6
Education level		
Secondary or lower, and post-secondary non-tertiary	178	78.4
University studies (tertiary)	45	21.6
Missing	4	
Employment status		
Unemployed	103	45.4
Still in education	44	19.4
Employed	80	35.2
Remuneration		
Paid work	71	31.2
Non-paid work	3	1.3
Missing	6	
Working time		
Full-time	48	21.1
Part-time	21	9.2
Missing	11	
Given always or most of the time tasks appropriate to their ability	70	30.8
Satisfied or very satisfied with their work capacity	67	29.5

CP, cerebral palsy.

Table 2 shows the main impairment characteristics by employment and higher education statuses. In models considering each impairment separately, individuals with more severe motor impairments (GMFCS IV–V or BFMF IV–V), with more severe communication difficulties (FCCS IV–V) and without understandable speech (VSS III–IV) were less likely to be employed or to have completed higher education. Visual impairment affected the odds of having a higher education qualification but did not significantly affect employment. On the contrary, individuals with seizures in the last year had significantly reduced odds of being employed whereas there was no difference in higher education qualification. The frequency or severity of pain and fatigue during the past 2 weeks were not associated with employment or higher education status. In the final multivariate models, individuals with the most severe gross motor function limitations (GMFCS IV–V) were significantly less likely to be employed (OR 0.23 (95% CI 0.09 to 0.56)) and had significantly less frequently completed higher education (OR 0.19 (95% CI 0.05 to 0.75)) than those with

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Table 2 Impairment characteristics, sociodemographic characteristics and environmental factors by employment and education status of young adults with CP without moderate to profound intellectual impairment (n=227)—SPARCLE3—France, Germany, Italy, Portugal and Sweden, 2018–2020

	Employment status*						Higher education status†					
	Unemployed (n=103)		Employed (n=80)				Secondary or lower (n=178)		Tertiary (n=45)			
	n	%	n	%	OR‡	95% CI	n	%	n	%	OR§	95% CI
Models considering each impairment separately												
GMFCS												
I–II. Independent walking ability	46	44.7	59	73.8	1.00	Ref	100	56.2	36	80.0	1.00	Ref
III. Walking ability with assistive devices	17	16.5	9	11.2	0.21	0.07 to 0.62¶	24	13.5	7	15.6	1.03	0.37 to 2.88
IV–V. No or severely limited walking ability (wheelchair)	40	38.8	12	15.0	0.12	0.05 to 0.29¶	54	30.3	2	4.4	0.12	0.03 to 0.53¶
BFMF												
I. Unilateral limitations in advanced fine motor skills	29	28.2	40	50.0	1.00	Ref	65	36.5	28	62.2	1.00	Ref
II–III. Unilateral restrictions to grasp and hold with no in-hand manipulation or worse, or bilateral restrictions in advanced fine motor skills	45	43.6	35	43.7	0.39	0.19 to 0.82¶	79	44.4	17	37.8	0.51	0.24 to 1.06
IV–V. Only grasp or worse with both hands	29	28.2	5	6.3	0.07	0.02 to 0.22¶	34	19.1	0	0.0	0.05	0.01 to 0.80¶
Visual impairment												
No	63	61.2	67	83.8	1.00	Ref	123	69.1	36	80.0	1.00	Ref
Yes, difficulty or inability to see, even if wearing glasses	40	38.8	13	16.2	0.25	0.12 to 0.55†	55	30.9	9	20.0	0.58	0.25 to 1.34
Speaking ability (Viking Speech Scale)												
I. Clearly or usually understandable	54	52.4	61	76.3	1.00	Ref	108	60.7	43	95.6	1.00	Ref
II. Imprecise but usually understandable to unfamiliar listeners	20	19.4	14	17.5	0.53	0.23 to 1.26	37	20.8	2	4.4	0.20	0.05 to 0.79¶
III–IV. No understandable speech or not usually understandable to unfamiliar listeners	29	28.2	5	6.2	0.09	0.03 to 0.27¶	33	18.5	0	0.0	0.04	0.01 to 0.70¶
FCCS												
I. Effective communication in most situations	62	60.2	71	88.8	1.00	Ref	128	71.9	45	100.0	1.00	Ref
II–III. Effective communication in most situations but does need some help	17	16.5	7	8.7	0.27	0.10 to 0.75¶	27	15.2	0	0.0	0.05	0.01 to 0.84¶
IV–V. Assistance required in most situations or communicates using undirected movement and behaviour	24	23.3	2	2.5	0.05	0.01 to 0.20¶	23	12.9	0	0.0	0.07	0.01 to 1.13
Fatigue over the last 2 weeks												
Not at all	33	33.7	23	28.7	1.00	Ref	54	31.2	12	27.7	1.00	Ref
Yes, at least several times	65	66.3	57	71.3	1.34	0.68 to 2.62	119	68.8	33	73.3	1.08	0.48 to 2.38
Missing	5		0				5		0			
Frequency of pain during the past 2 weeks												
None	36	34.9	26	32.5	1.00	Ref	62	34.8	12	26.7	1.00	Ref
Once or twice	19	18.5	20	25.0	1.63	0.69 to 3.82	12	21.4	12	26.7	1.37	0.52 to 3.31

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Table 2 Continued

	Employment status*						Higher education status†					
	Unemployed (n=103)		Employed (n=80)				Secondary or lower (n=178)		Tertiary (n=45)			
	n	%	n	%	OR‡	95% CI	n	%	n	%	OR§	95% CI
Frequent	48	46.6	34	42.5	1.09	0.53 to 2.24	21	43.8	21	46.6	1.05	0.45 to 2.48
Severity of pain during the past 2 weeks												
None	35	34.3	26	32.5	1.00	Ref	61	34.7	12	26.7	1.00	Ref
Very mild to moderate	46	45.1	48	60.0	1.60	0.80 to 3.22	84	47.7	32	71.1	1.41	0.64 to 3.10
Severe or very severe	21	20.6	6	7.5	0.41	0.14 to 1.22	31	17.6	1	2.2	0.19	0.03 to 1.13
Missing	1		0				2		0			
Seizures during the last year												
No	87	84.5	76	95.0	1.00	Ref	157	88.2	45	100.0	1.00	Ref
Yes	16	15.5	4	5.0	0.20	0.06 to 0.65¶	21	11.8	0	0.0	0.12	0.01 to 2.05
Multivariate model with impairments												
GMFCS												
I–II. Independent walking ability	46	33.6	59	43.1	1.0	Ref	100	73.5	36	26.5	1.00	Ref
III. Walking ability with assistive devices	17	54.9	9	29.0	0.28	0.10 to 0.82¶	24	77.4	7	22.6	1.24	0.44 to 3.52
IV–V. No or severely limited walking ability (wheelchair)	40	67.8	12	20.3	0.23	0.09 to 0.56¶	54	96.4	2	3.6	0.19	0.05 to 0.75¶
FCCS												
I. Effective communication in most situations	62	35.6	71	40.8	1.0	Ref						
II–III. Effective communication in most situations but does need some help or have small range of messages/topics to most familiar people	17	63.0	7	25.9	0.36	0.12 to 1.05						
IV–V. Assistance required in most situations or communicates using undirected movement and behaviour	24	92.3	2	7.7	0.05	0.01 to 0.25¶						
Speaking ability (Viking Speech Scale)												
I. Clearly or usually understandable							108	71.5	43	28.5	1.00	Ref
II. Imprecise but usually understandable to unfamiliar listeners							37	94.9	2	5.1	0.21	0.05 to 0.75¶
III–IV. No understandable speech or not usually understandable to unfamiliar listeners							33	100.0	0	0.0	0.06	0.05 to 0.85¶
Models considering each sociodemographic characteristic separately												
Population size of area of residence												
>200 000	30	29.4	30	37.5	1.40	0.58 to 3.39	62	35.0	22	48.9	1.08	0.45 to 2.61
3000–200 000	56	54.9	30	37.5	1.00	Ref	81	45.8	20	44.4	1.00	Ref
<3000	16	15.7	20	25.0	2.55	0.90 to 7.18	34	19.2	3	6.7	0.35	0.09 to 1.33
Missing	1		0				1		0			

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Table 2 Continued

	Employment status*						Higher education status†					
	Unemployed (n=103)		Employed (n=80)				Secondary or lower (n=178)		Tertiary (n=45)			
	n	%	n	%	OR‡	95% CI	n	%	n	%	OR§	95% CI
Lifestyle												
With parents, in care facilities or other	87	84.5	50	62.5	1.00	Ref	137	77.0	27	60.0	1.00	Ref
Independently	16	15.5	30	37.5	2.38	0.93 to 6.09	41	23.0	18	40.0	1.74	0.70 to 4.34
Higher education status												
Secondary or lower, and post-secondary non-tertiary	93	93.9	55	68.7	1.00	Ref						
University studies (tertiary)	6	6.1	25	31.3	9.37	2.87 to 30.64¶						
Missing	4		0									
Highest parental education level												
Primary and/or lower secondary	34	34.7	25	31.2	1.00	Ref	61	35.2	11	24.4	1.00	Ref
Upper secondary and/or Bachelor	41	41.8	27	33.8	0.76	0.29 to 1.97	70	40.5	8	17.8	0.72	0.23 to 2.23
Master and/or Doctorate	23	23.5	28	35.0	1.94	0.65 to 5.79	42	24.3	26	57.8	2.35	0.97 to 8.73
Missing	5		0				5		0			
Models considering each environmental factor separately												
Accessible public transport (buses/trains/taxis)												
Unmet need	19	18.4	11	13.9	1.00	Ref	31	17.5	7	15.6	1.00	Ref
Met need	84	81.6	68	86.1	0.71	0.25 to 2.08	146	82.5	38	84.4	0.79	0.25 to 2.48
Missing	0		1				1		0			
Adequate public transport (buses/trains/taxis)												
Unmet need	19	18.5	13	16.5	1.00	Ref	31	17.5	5	11.1	1.00	Ref
Met need	84	81.5	66	83.5	0.70	0.27 to 1.83	146	82.5	40	88.9	1.54	0.46 to 5.16
Missing	0		1				1		0			
Adapted vehicle												
Unmet need	14	13.6	12	15.0	1.00	Ref	29	16.3	9	20.0	1.00	Ref
Met need	89	86.4	68	85.0	0.60	0.21 to 1.74	149	83.7	36	80.0	1.07	0.39 to 2.89
Accessible car parking in places where need to park												
Unmet need	32	31.4	12	15.0	1.00	Ref	42	23.7	10	22.2	1.00	Ref
Met need	70	68.6	68	85.0	3.30	1.28 to 8.55¶	135	76.3	35	77.8	0.80	0.30 to 2.15
Missing	1		0				1		0			
Grants for travel												
Unmet need	35	34.0	13	16.3	1.00	Ref	43	24.2	8	17.8	1.00	Ref
Met need	68	66.0	67	83.8	1.49	0.61 to 3.63	135	75.8	37	82.2	1.16	0.43 to 3.12

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Table 2 Continued

	Employment status*						Higher education status†					
	Unemployed (n=103)		Employed (n=80)				Secondary or lower (n=178)		Tertiary (n=45)			
	n	%	n	%	OR‡	95% CI	n	%	n	%	OR§	95% CI
Information about education/employment												
Unmet need	50	51.0	21	26.3	1.00	Ref	67	38.7	9	20.0	1.00	Ref
Met need	48	49.0	59	73.8	1.50	0.67 to 3.40	106	61.3	36	80.0	1.92	0.75 to 4.91
Missing	5		0				5		0			
Adapted equipment												
Unmet need	3	3.0	4	5.0	1.00	Ref	7	4.0	2	4.4	1.00	Ref
Met need	96	97.0	76	95.0	0.60	0.09 to 3.90	167	96.0	43	95.6	0.98	0.13 to 7.54
Missing	4		0				4		0			
Encouragement from family/friends												
Unmet need	5	4.9	6	7.6	1.00	Ref	9	5.1	3	6.7	1.00	Ref
Met need	98	95.1	73	92.4	0.42	0.09 to 1.97	168	94.9	42	93.3	0.93	0.19 to 4.53
Missing	0		1				1		0			
Emotional support from family/friends												
Unmet need	3	2.9	2	2.5	1.00	Ref	7	4.0	0	0.0	1.00	Ref
Met need	100	97.1	77	97.5	0.84	0.17 to 4.19	170	96.0	45	100.0	–	–
Missing	0		1				1		0			

*Young adults who were still in education at interview (n=44) were excluded from analysis.
†Young adults who did not complete information about higher education status (n=4) were excluded from analysis.
‡All unconditional logistic regression models were adjusted for region. Models considering each sociodemographic characteristic and each environmental factors separately were also adjusted for GMFCS and FCCS.
§All unconditional logistic regression models were adjusted for region and age. Models considering each sociodemographic characteristic and each environmental factors separately were also adjusted for GMFCS and speaking ability.
¶ 95% CI excluding 1.00.
BFMF, Bimanual Fine Motor Function; CI, Confidence interval; CP, cerebral palsy; FCCS, Functional Communication Classification System; GMFCS, Gross Motor Function Classification System; OR, Odds Ratio.

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mild or moderate gross motor restrictions (GMFCS I–II). Similarly, the odds of being employed were significantly reduced for individuals with GMFCS III (OR 0.28 (95% CI 0.10 to 0.82)) and with communication difficulties (FCCS IV–V, OR 0.05 (95% CI 0.01 to 0.25)). Having imprecise speech (VSS II) or having no understandable speech (VSS III–IV) were associated with reduced odds of completing higher education (OR 0.21 (95% CI 0.05 to 0.75) and (OR 0.02 (95% CI 0.05 to 0.85)), respectively).

Whatever the severity of their motor impairment and communication difficulties, young adults with CP who completed higher education were more likely to be employed (OR 9.37 (95% CI 2.87 to 30.64)). We observed no differences in employment or higher education status according to population size of the area of residence, lifestyle or parental education level (table 2).

For individuals living in an environment that met their needs in terms of accessibility to car parking, the odds of being employed (OR 3.30 (95% CI 1.28 to 8.55)) were significantly higher compared with those with unmet needs. We observed no differences in employment or higher education status for all other environmental characteristics, whether physical, social or attitudinal needs (table 2).

In the subsample of 93 young adults who were not still in education and who had previously participated in the SPARCLE cohort, we found that mainstream schooling during childhood significantly increased the odds of being employed in young adulthood (OR 11.71 (95% CI 1.04 to 131.66)). The effect was greater when mainstream schooling was continued during adolescence (OR 16.14 (95% CI 1.33 to 195.12)), independently of the severity of motor and communication impairments (table 3).

In the overall sample, compared with the unemployed, young adults who were employed reported significantly higher QoL in the physical well-being domain by 8.55 points (95% CI 3.19 to 13.91) and in the psychological well-being domain by 7.98 points (95% CI 2.88 to 13.08) (table 4).

DISCUSSION

In accordance with the Convention on the Rights of Persons with Disabilities[38] promoting full participation in socially expected roles, we explored higher education status and employment status as markers of integration in young adulthood. We showed that, overall, 45.4% of young adults with CP and an IQ ≥50 were neither in higher education nor in employment. Of those who were employed (35.2%), more than 4 in 5 reported being paid, being given tasks appropriate to their abilities, or being satisfied with their work capacity. The likelihood of employment was significantly reduced (by more than 75%) for young people with severe gross motor limitations or severe communication difficulties compared with less severely impaired participants. The probability of obtaining a higher education degree was reduced by a factor of 0.19 for young people with severe gross motor impairments and by 0.02 for those with imprecise or non-understandable speech. Having a higher education qualification and having attended a mainstream school during childhood, or continued mainstream education until adolescence were found to be powerful levers for access to employment (12-fold and 16-fold increases in the odds of being employed, respectively). Except for the accessibility of car parking when needed, none of the environmental factors studied significantly influenced employment or higher education status, after adjustment for

Table 3 Inclusion or insertion in mainstream education during childhood and/or adolescence by employment and education status of young adults with CP without moderate to profound intellectual impairment (n=113)—SPARCLE3—France, Germany, Italy and Sweden, 2018–2020

	Employment status*						Higher education status					
	Unemployed (n=42)		Employed (n=51)				Secondary or lower (n=90)		Tertiary (n=23)			
	n	%	n	%	OR†	95% CI	n	%	n	%	OR‡	95% CI
Inclusion or insertion in mainstream school in childhood or in adolescence												
No	9	21.4	11	21.6	1.00	Ref	20	22.2	0	0.0	1.00	Ref
Yes	33	78.6	40	78.4	9.13	0.84 to 99.46	70	77.8	23	100.0	5.79	0.37 to 90.66
In childhood	29	69.0	40	78.4	11.71	1.04 to 131.66§	64	71.1	23	100.0	6.26	0.41 to 94.52
Only in childhood	8	19.0	4	7.9	–	–	12	13.3	2	8.7	2.89	0.15 to 56.77
In adolescence	25	59.5	36	70.6	8.68	0.79 to 95.90	58	64.4	21	91.3	8.71	0.52 to 146.28
Only in childhood	4	9.5	0	0.0	–	–	6	6.7	0	0.0	–	–
In childhood and adolescence	21	50.0	36	70.6	16.14	1.33 to 195.12§	52	57.8	21	91.3	9.82	0.58 to 165.35

*Young adults who were still in education at interview (n=20) were excluded from analysis.
†All unconditional logistic regression models were adjusted for region, GMFCS and FCCS.
‡All unconditional logistic regression models were adjusted for region, age, GMFCS and speaking ability.
§95% CI excluding 1.00.
CI, Confidence Interval; CP, cerebral palsy; FCCS, Functional Communication Classification System; GMFCS, Gross Motor Function Classification System; OR, Odds Ratio.

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Table 4 Distribution and variation of QoL by employment status of young adults with CP without moderate to profound intellectual impairment (n=227)—SPARCLE3—France, Germany, Italy, Portugal and Sweden, 2018–2020

	Physical well-being	Psychological well-being	Social relationships	Environment
Employment status				
Unemployed				
n	103	100	103	103
Mean (SD)	62.4 (20.4)	67.8 (16.7)	68.6 (23.0)	72.1 (14.7)
(min–max)	(10.7–96.42)	(16.7–100.0)	(8.3–100.0)	(31.2–100.0)
Employed				
n	80	80	80	80
Mean (SD)	75.0 (14.6)	75.1 (15.6)	72.2 (19.1)	76.2 (14.3)
(min–max)	(28.6–84.4)	(37.5–100.0)	(16.7–100.0)	(43.7–100.0)
Difference in QoL scores*				
β (95% CI)	8.55 (3.19 to 13.91)†	7.98 (2.88 to 13.08)†	0.84 (–5.74 to 7.43)	3.33 (–1.35 to 8.02)

*All linear regression models were adjusted for region and GMFCS and FCCS. β coefficients show the average difference in quality of life by employment status (with unemployed as reference).
†95% CI excluding zero.
CI, Confidence Interval; CP, cerebral palsy; FCCS, Functional Communication Classification System; GMFCS, Gross Motor Function Classification System; QoL, quality of life.

impairments. Young adults who were employed reported significantly higher physical and psychological well-being than those without employment.

Based on eight studies, the meta-analysis by van Gorp *et al*[25] reported a mean weighted rate of completed higher education of 18.2% (95% CI 10.6 to 27.2), similar to our findings. The authors identified four studies of adults with and without intellectual disability that reported an employment rate with a mean weighted proportion of 55.5% (95% CI 31.5 to 78.3), higher than that of our study. This discrepancy may be due to differences in the populations studied. The exclusion criteria of intellectual disability applied in these studies used different definitions (such as 'no learning deficiency' or 'no cognitive impairment preventing understanding the study instructions'), or a stricter criterion (IQ >70), which may have selected individuals who were more likely to be employed than those in our study. Also, with one exception, all these studies included a wider age range, making comparison with our sample difficult. Moreover, given that our sample was younger than those in the other studies, a substantial proportion was still in education (19.4%). Most of these young adults can be expected to be eligible for employment, bringing the proportion of employment closer to that found in the meta-analysis. This hypothesis may be supported by the fact that young adults who were still in education did not differ significantly in any of the factors studied from those who were employed, except that they were younger (online supplemental table 1). While the observed employment rate remained low, those who worked generally reported satisfactory employment conditions. Nevertheless, further studies comparing them with their peers of the same age in the general population will be needed to position their working conditions more accurately.

As impairments were the main barriers to the participation of people with disabilities identified so far, we examined them closely and found that severe motor and communication impairments were the most detrimental factors to achieving higher education or accessing employment. To our knowledge, these findings in relation to higher education levels have never been studied and should therefore be replicated. Regarding employment, three previous studies[22 24 26] support our finding that severe motor impairment was strongly associated with reduced employment rates. Among them, a recent Swedish cross-sectional registry-based study[24] also found that reduced communication ability was significantly associated with a lower employment rate. It should be noted that motor and communication impairments, when severe, independently reduced access to employment but that the effects were mediated by higher educational level, as was also observed in a Dutch cross-sectional study.[39] The role of comorbidities is less clear. The association between seizures and employment reported by Michelsen *et al*[22] appeared non-significant after the analysis was adjusted on impairments. Lastly, as suggested by Pettersson and Rodby-Bousquet,[24] we performed the analysis with fatigue, which was experienced by more than two-thirds of respondents, but we found no association.

An Australian study[40] investigated the role of environmental factors in education and employment in young adults with CP aged 18–25 years. For education and employment, study participants reported that the lack of transport access (35.8% and 42.2%, respectively) and the lack of family help or assistance (21.5% and 25.3%, respectively) somewhat or greatly affected their participation. Our study adds information by being the first to examine associations between environmental factors and higher education and

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employment. Of the 61 EAEQ items, we selected a priori nine items for their relevance in potentially modifying the level of education achieved or the employment status,[41] with the hypothesis that unmet environmental needs may act as barriers. We found no significant association between these two outcomes, except for access to car parking which seemed to increase the employment rate. Another option would have been to consider the environment as a whole, hypothesising that a combination of barriers may have an impact. The fact that we did not observe any association does not minimise the role of an appropriate environment in increasing the social participation of young adults with CP. It is interesting to note that six of the nine environmental factors studied were largely met when needed (>80%) regardless of higher education completion or employment status. This encouraging observation suggests that other meaningful daily activities (such as going to an activity centre or meeting friends) may also be more frequent.

Unsurprisingly, and in line with the OECD observations for the general population,[42] we found that completion of a higher education degree was an important determinant of employment among young adults with CP. Our findings also suggested that the role of education may be determinant from an early age and may be stronger when the social inclusion process is maintained in adolescence. However, due to the small sample size and the fact that our mainstream school data (collected once in childhood and once in adolescence) was not intended to capture the entire school career, this finding should be interpreted with caution.

The perceptual and subjective aspects of QoL seem to us to be relevant in understanding the role of employment, as effective inclusion, in the daily life of young adults with CP. Whatever their region, motor functions or communication ability, we observed that individuals with CP who were employed had a significantly higher mean QoL score in the physical and psychological well-being domains. This highly positive finding supports the hypothesis that full and successful inclusion in society may help to improve the perception that the person with CP has of his or her position in life. Nevertheless, being employed did not increase their satisfaction with social relationships, although work might have been expected to be a factor in favour of social relations. In a previous study,[43] we hypothesised that factors associated with lower QoL in the social relationships domain may indirectly reflect limited access to employment. Our current study did not support this hypothesis. Finally, to our knowledge, this cross-sectional analysis is the first of its kind in adults with CP and should be replicated in further studies, particularly those able to establish the temporal relationship between employment and QoL, such as cohort studies.

In this cross-sectional study, we identified cases from population-based registries in five European regions and from several independent sources in two additional regions using the same definition of CP, which limited case selection and classification errors. Nevertheless, we cannot document to what extent our sample is representative of the CP population of the countries studied, due to the regional coverage of registries and the impossibility of comparing the distribution we observed with external sources. Our results should therefore be interpreted with caution in terms of generalisability. We can only compare the sample characteristics with those of previous studies. For individuals who have participated in the SPARCLE cohort since they were children and/or adolescents, previous analyses[43] showed a significant increase in dropout rate among young adults with at least one parent who did not complete secondary education. This differential attrition might overestimate the distribution of employment and higher education. The effect on observed distribution of intentional overrepresentation of the most severe phenotypes is difficult to quantify because we excluded from our sample young adults with an IQ <50or equivalent. Overall, we collected data with validated measurement tools during standardised interviews and there were very few missing data. Despite the small sample size of the subgroup of individuals longitudinally followed and limited data on mainstream schooling during youth, we found a major and significant effect of mainstream schooling on employment status. On this point, as on others in this paper, the data should be replicated.

In conclusion, the employment situation of young adults with CP can still be improved, but our findings encourage the implementation of inclusive policies from an early age. For people with CP with severe motor and communication impairments, the use of modern, sophisticated, intelligent technology for communication and mobility covered by the educational, disability services or healthcare services may greatly enhance school and work careers.

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Contributors NVEB and CA conceived and designed the analysis. NVEB performed the final data analyses and prepared all sections of the manuscript. MS supervised the study. The core-writing group for this manuscript consisted of NVEB, CP, CA and MS. All authors have reviewed and approved the final version. CA is the guarantor of this study.

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Patient consent for publication Consent obtained directly from patient(s).

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Differences in participation between young adults with cerebral palsy and their peers: A cross-sectional multicentre European study

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ABSTRACT

Background: Children and adolescents with disabilities are known to participate less in most areas of life than their non-disabled peers.
Objectives: (1) To estimate differences in participation between young adults with cerebral palsy (CP) and their non-disabled peers; (2) to test the mediating role of financial difficulties and student status; (3) to test the moderating role of personal factors on participation difference; and (4) to test the moderating role of impairment.
Methods: A cross-sectional study was conducted in young adults [19–28 years] with CP (n = 228) and non-disabled peers (n = 2861) in France, Germany and Sweden. Participation was assessed using the Questionnaire of Young People's Participation adapted for young adults (QYPP-YA). Differences in five domains of participation were estimated using structural equation modeling with WLSMV method and bias-corrected bootstrap confidence intervals.
Results: Young adults with CP showed lower participation than others in all domains, with the largest difference in the "intimate relationships" domain ($\beta = 1.71$ bcCI95[1.46; 1.95]). Student status mediated the difference in "intimate relationships", "interpersonal relationships" and "independence". Women showed greater differences than men on "independence". Impairments moderated difference in participation. The less severely impaired young adults showed no difference with their non-CP peers in "interpersonal relationships", "social life" and "independence", but made autonomous everyday decisions more often than their peers.
Conclusions: Young adults with CP do not have the same opportunities to attain the participation level of non-CP people of the same age. Continuance of education could help to reduce participation difference in "interpersonal relationships" and "independence".

1. Introduction

According to the United Nations Convention on the Rights of Persons with Disabilities "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".[1] Participation, considered as a construct composed of attendance and involvement,[2] is a major outcome for people with disabilities. Much of the recent literature on adults with cerebral palsy (CP) has addressed "Activities and Participation".[3] For young adults, "participation in major life areas" has received attention from reserachers[3] as this transitional period appears to have important outcomes for persons with CP.[4]

Differences in participation compared with non-CP peers have been demonstrated in the few existing studies specifically addressing young

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Abbreviations

bcCI	bias corrected bootstrap confidence interval
CFI	Comparative Fit Index
CP	Cerebral Palsy
df	degree of freedom
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
IQ	Intellectual Quotient
QYPP-YA	Questionnaire of Young People's Participation – Young Adults version
RMSEA	Root Mean Square Error of Approximation
SD	Standard Deviation
SPARCLE	Study of PARticipation of Children with cerebral palsy Living in Europe
TLI	Tucker-Lewis Index
WLSMV	Weigthed Least Square with Mean and Variance adjusted
WRMR	Weighted Root Mean square Residual

variety of domains including community life, interpersonal and intimate relationships.[5] Factors suggested to relate to lesser participation by young adults with CP were sex, self-esteem, physical ability, and type and severity of impairment.[5,6]

The effect of sociodemographic characteristics on participation has been studied. Social participation was observed to differ according to sex and age, with men and older people being less likely to be involved in social relationships.[5,7–11] Social participation increased from childhood up to adolescence and then, depending on pursuit of education or working life, decreased in older adulthood.[11–14] In addition to functional issues, household income and age showed direct effects on participation at home in children with and without CP.[9,15,16] Lastly, various authors observed that socioeconomic status or income appeared to be important determinants of participation in various studies.[17–21] Based on the International Classification of Functioning, Disability and Health (ICF), socioeconomic status and student status were considered as contextual factors, while sex, age, country, population size of area of residence and parental level of education were considered as personal factors.

There is a lack of knowledge about how people with CP compare with their non-disabled peers during young adulthood, and about significant determinants of participation. The present study aimed (1) to estimate the difference in participation between young adults with CP and their non-disabled peers, (2) to test the mediating role of contextual factors

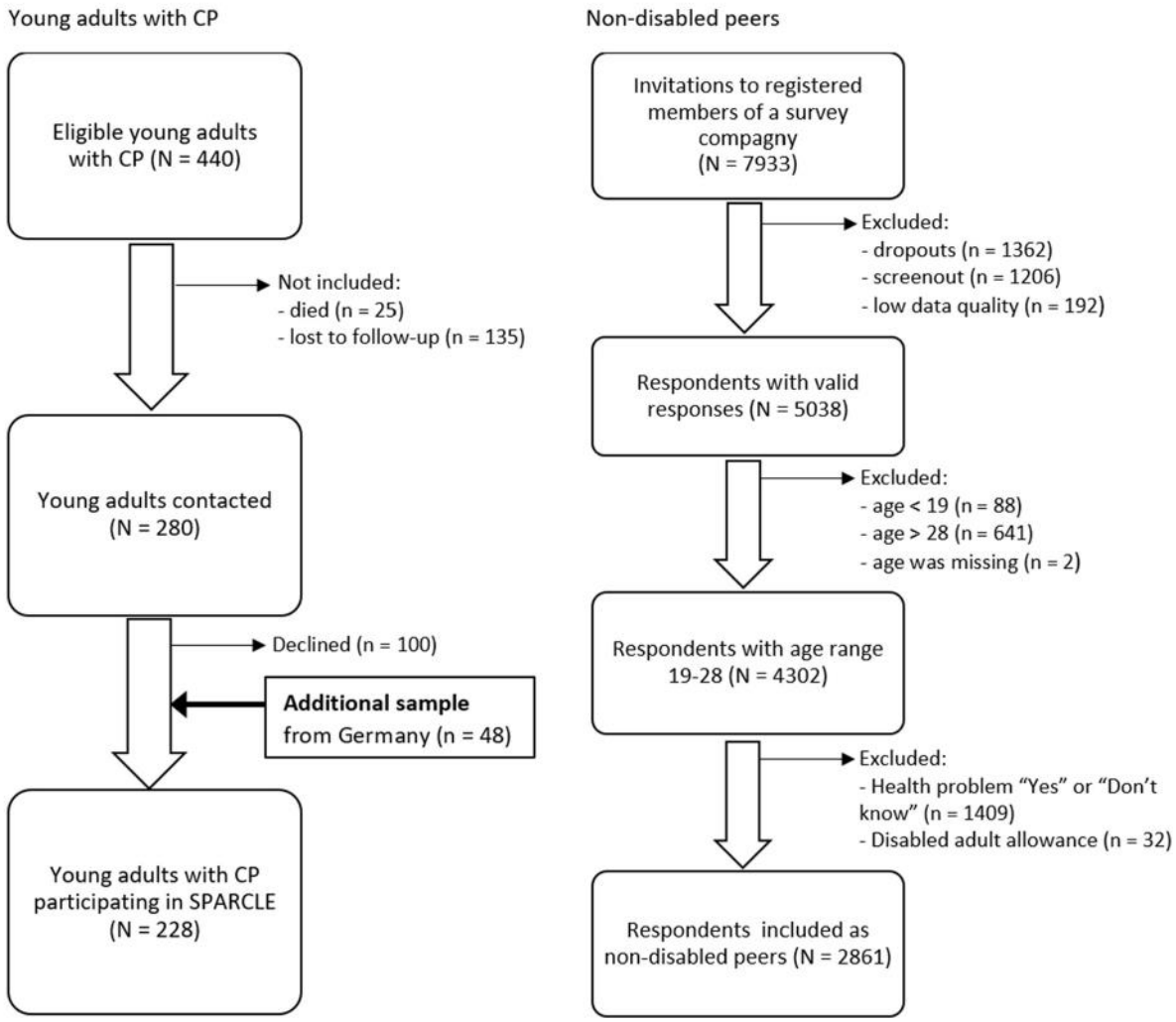


Fig. 1. Flowchart of participant inclusion.

adults with CP. They participated less than their non-CP peers in a

(financial difficulties and student status), (3) to test the moderating role

Table 1
Completion questionnaire status in SPARCLE 3 and intellectual impairment in SPARCLE 2.

	Completion questionnaire status in SPARCLE 3			
	Self-reported without assistance	Self-reported with assistance	Proxy report	Total
Intellectual level of impairment in SPARCLE 2[a]				
IQ > 70	50 (83.3)	14 (35.0)	0 (0)	64 (44.1)
IQ 50-70	10 (16.7)	22 (55.0)	6 (13.3)	38 (26.2)
IQ < 50	0 (0)	4 (10.0)	39 (86.7)	43 (29.7)
Total	60 (100)	40 (100)	45 (100)	145 (100)

Note: Test for correlation was significant ($p < 0.001$).
[a] The SPARCLE cohort is a multicenter European study designed to study participation and quality of life in individuals with CP interviewed at childhood, adolescence and young adulthood. In SPARCLE 2nd wave, the intellectual level of impairment of 667 adolescents with CP was collected from nine European regions. Here we compared the intellectual level of impairment in SPARCLE 2 to the completion questionnaire status in SPARCLE 3 of the same young people with CP from Northern Germany, Southwest France, Southeast France and Western Sweden.

of personal factors (sex, age, country, population size of area of residence and parental level of education) on participation, and (4) to test the moderating role of impairment.

2. Method

2.1. Study design and participants

We conducted a multicentre cross-sectional study as part of SPARCLE 3.[22] SPARCLE is a multicentre European study designed to study participation and quality of life in individuals with CP interviewed at childhood, adolescence and young adulthood.From August 2018 to March 2020, research associates conducted face-to-face interviews with young adults with CP. Self-report was obtained whenever possible. If not possible, a proxy or the research associate could assist young people with motor or communication difficulties to complete the questionnaires by explaining questionnaire instructions, scales or items and answering questions. In order to include young people with severe impairment, when young adults were unable to respond themselves even when assisted, the research associate interviewed a proxy who knew the young adult well (parents or very rarely carers/personal assistants). The same set of questionnaires, with the exception of those specific to impairment, was administered online from May 2019 to February 2020 to a sample of young adults from the general population.

Participants with CP born between 1991 and 1997 were identified from the CP registers in France and Sweden. They were invited to take part in the study. As there is no CP registry in Germany, young adults with CP living in Northern Germany and aged 19 to 28 were recruited from youth rehabilitation centers, paediatric hospitals or institutions for people with intellectual disabilities. For comparaison, young adults living in France, Germany and Sweden were recruited among registered members of a survey company. A link to the online questionnaire was distributed equally to young men and women aged between 19 and 29. As an incentive, participants were awarded points which they accumulated and could redeem for a voucher. A quality control process was then applied (Appendix A1). Only young adults with no long-standing illnesses or health problems were included in this analysis. The study samples are described in a flowchart (Fig. 1). Participants gave their informed consent, or their non-opposition to participate where applicable. The relevant ethics and regulatory approvals were obtained. All data were anonymous.

Table 2
Participant characteristics.

	Young adults with CP (n = 228)	General population (n = 2861)	*P*-value (χ test)
Sex			0.131
Male	127 (55.7)	1445 (50.5)	
Female	101 (44.3)	1416 (49.5)	
Age			0.3068[F]
Mean (SD)	23.68 (2.08)	23.88 (2.90)	
Population size of area of residence (n inhabitants)			**<0.001**
Large city or outskirts (>200.000)	96 (42.1)	1250 (43.7)	
Town (3.000–200.000	78 (34.2)	1222 (42.7)	
Rural area (<3.000)	54 (23.7)	388 (13.6)	
Parental level of education			0.743
University studies	46 (20.7)	657 (23.0)	
Upper secondary/short tertiary cycle	90 (40.5)	1121 (39.2)	
Primary/Lower secondary	86 (38.7)	1083 (37.8)	
Financial difficulties			**0.028**
Living comfortably	81 (36.5)	813 (29.0)	
Coping with income	101 (45.5)	1524 (54.4)	
Difficult/Very difficult with income	40 (18.0)	465 (16.6)	
Student status			**0.004**
Out of school	192 (84.2)	2109 (75.8)	
Student (not paid for by employer)	36 (15.8)	675 (24.3)	
Country			**<0.001**
Germany	110 (48.2)	916 (32.0)	
Sweden	30 (13.2)	600 (21.0)	
France	88 (36.6)	1345 (47.0)	
CP type			
Spastic unilateral	60 (26.4)		
Spastic bilateral	134 (59.0)		
Dyskinetic	18 (7.9)		
Dyskinetic choreo-athetotic	3 (1.3)		
Ataxic	12 (5.3)		
GMFCS			
Reference		2861 (100)	
Level I	78 (34.2)		
Level II	28 (12.3)		
Level III	32 (14.0)		
Level IV	51 (22.4)		
Level V	39 (17.1)		
BFMF			
Reference		2861 (100)	
Level I	70 (30.7)		
Level II	58 (25.4)		
Level III	35 (15.4)		
Level IV	38 (16.7)		
Level V	27 (11.8)		
Questionnaire completion status			
Reference		2861 (100)	
Report without assistance	96 (42.1)		
Report with assistance	62 (27.2)		
Proxy report	70 (30.7)		

SD stands for Standard Deviation; [F] stands for Fisher-test; GMFCS stands for Gross Motor Function Classification Scale; BFMF stands for Bimanual Fine Motor Function.

2.2. Measures

The Questionnaire of Young People's Participation[23] was written for adolescents with CP aged 12–18. It was later adapted for young adults based on results obtained in focus groups.[24] This new version, the QYPP-Young Adults (QYPP-YA), covers participation in major domains of life. Respondents answer on 5 or 7-point Likert scales from the highest

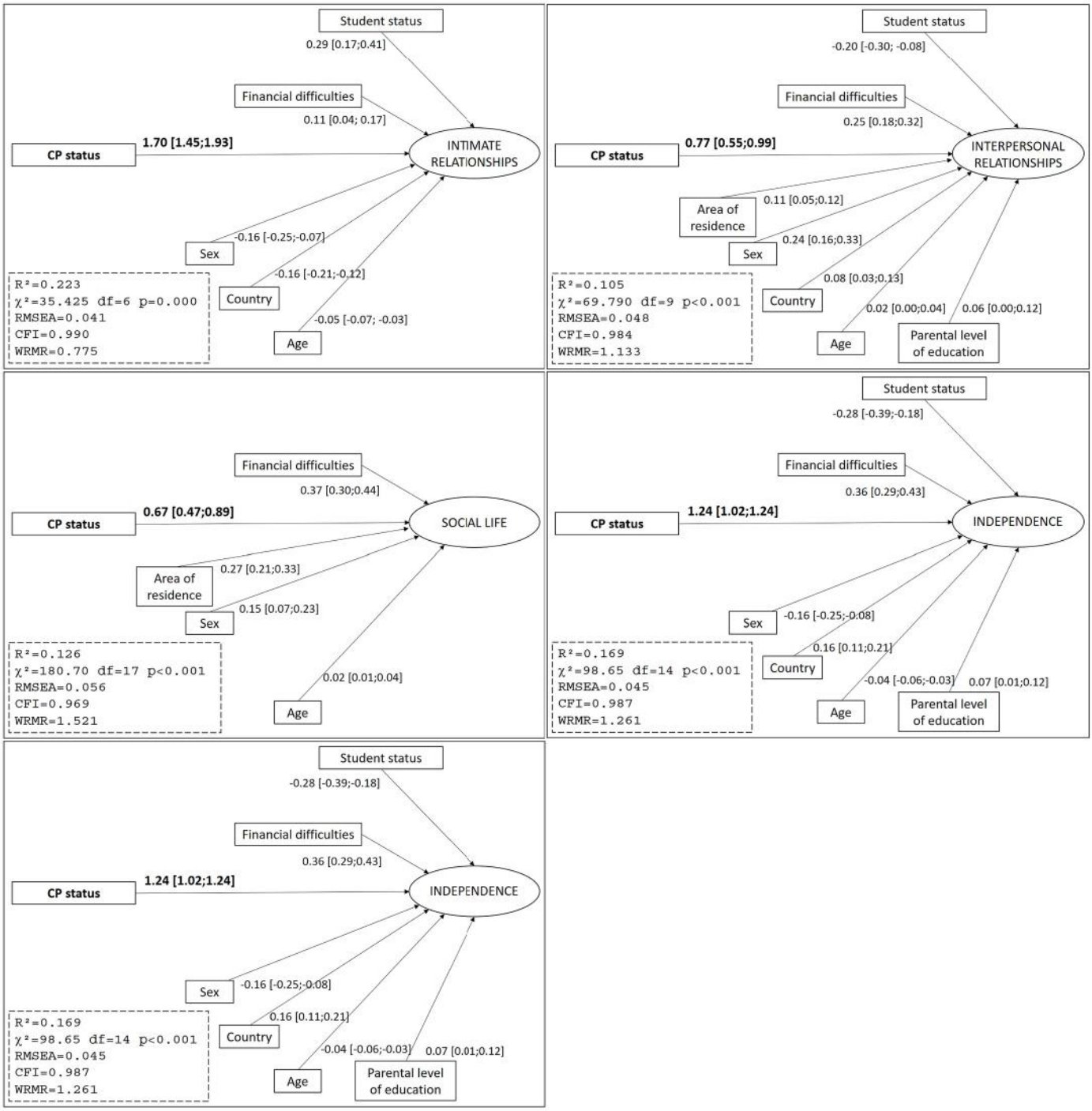


Fig. 2. Structural models for participation domains

Rectangles represent indicators and ovals latent participation scores. "CP status" was tested to explain the participation scores taking into account confounders. Unstandardized coefficients are reported with bias-corrected bootstrap confidence intervals. These coefficients are all significant. "CP status" opposed young adults with CP to their peers (reference); "Area of residence" ranged from big cities to rural area; "Sex" opposed women to men (reference); "Country" was recorded as Germany, Sweden, France; "Age" was centered; "Parental level of education" varied from high to low level; "Financial difficulties" ranged from living comfortably to living with difficulties; "Student status" was opposed to out-of-school situations (reference). *How to read this?* For one change from "Non CP-peers" to "young adult with CP", the latent participation in "intimate relationships" increased by 1.71 units, with similar situations for sex, country, age, financial difficulties and student status.

frequency of involvement (1 = "Always") to no participation (5 = "Never" or 7 = "Never") (questionnaire, Appendix A2). Preliminary analyses have identifyed six latent scales: "intimate relationships" (2 items), "interpersonal relationships" (2 items), "social life" (4 items) including community recreation, "independence" (3 items) including independent living, freedom of choice and self-reliance, "autonomy" (4 items) including self-determination and everyday life decision-making, as well as "online communication" (2 items) (Appendix A3). We excluded the "online communication" scale from this analysis because of bias due to online data collection for non-CP peers.

Self-administered questionnaires were used to collect sex, age, population size of area of residence, parental level of education, perceived

Table 3
Total mediating effects of financial difficulties and student status (separated models).

	INTIMATE	INTERPERSONAL	SOCIAL	INDEPENDENCE	AUTONOMY
	Estimate [bcCI95]	Estimate [bcCI95]	Estimate [bcCI95]	Estimate [bcCI95]	Estimate [bcCI95]
M1 Financial Difficulties					
Direct effect					
CP status on PART	1,71 [1,47; 1,96]	0.74 [0.52; 0.94]	0,67 [0,47; 0,87]	1,23 [1,02; 1,43]	0,23 [-0,01; 0,48]^{ns}
Indirect effects					
Financial difficulties on PART	0,11 [0,05; 0,18]	0.25 [0.18; 0.32]	0,37 [0,3; 0,44]	0,36 [0,3; 0,43]	0,28 [0,21; 0,36]
CP status on financial difficulties	−0,03 [-0,13; 0,06]^{ns}	−0.02 [-0.12; 0.08]^{ns}	−0,06 [-0,15; 0,03]^{ns}	−0,02 [-0,12; 0,08]^{ns}	−0,03 [-0,13; 0,06]^{ns}
Total effects	-	-	-	-	-
Fit indices					
RMSEA [CI90]	0.059 [0.05; 0.07]	0.069 [0.06; 0.08]	0.059 [0.05; 0.07]	0.065 [0.06; 0.07]	0.074 [0.07; 0.08]
CFI/TLI	0.969/0.944	0.949/0.919	0.962/0.944	0.967/0.948	0.926/0.889
WRMR	1.609	2.142	1.711	2.052	2.256
M2 Student status					
Direct effect					
CP status on PART	1,71 [1,46; 1,96]	0,77 [0,54; 0,98]	–	1,23 [1,02; 1,44]	0,25 [-0.00; 0,49]^{ns}
Indirect effects					
Student status on PART	0,29 [0,17; 0,41]	−0,19 [-0,29; −0,08]	–	−0,28 [-0,39; −0,18]	−0,29 [-0,39; −0,19]
CP status on student status	−0,09 [-0,14; −0,04]	−0,08 [-0,14; −0,03]	–	−0,09 [-0,14; −0,04]	−0,08 [-0,13; −0,03]
Total effects	**1,68 [1,44; 1,95]**	**0,78 [0,58; 0,98]**	–	**1,25 [1,08; 1,44]**	**0,27 [0,05; 0,49]**
Fit indices					
RMSEA [CI90]	0.091 [0.08; 0.10]	0.096 [0.09; 0.10]	–	0.090 [0.08; 0.10]	0.087 [0.08; 0.09]
CFI/TLI	0.927/0.868	0.899/0.839	–	0.934/0.896	0.895/0.843
WRMR	2.450	3.027	–	2.875	2.620

"CP status" opposed young adults with CP to their peers (reference); PART refers to the latent participation variable. ^{ns} stands for "non-significant". When an indirect effect was non-significant, the total effect was not calculated.
How to read this? For one change from "Peers" to "Young adult with CP", the latent participation in intimate relationships increased by 1.68 units, taking into account indirect effects of student status limiting this gap, with similar situations for sex, country, age and financial difficulties. Student status has a partial mediation effect.

financial difficulties, and student status of both populations. The highest qualification of each parent was asked. When the level of qualification was reported for both parents, the median level was retained. The question: "How do you feel about your personal income nowadays" was asked to assess perceived financial difficulties. Student status variable was coded 1 for the answer "in education" to the question "Which of these descriptions best describes situation?". Answers were "working full-time in paid work", "working part-time in paid work", "in non-paid work", "in education", "unemployed", "permanently sick or disabled", "other" and "I don't know". Participants' country of residence was also retained as an indicator.

Research associates captured CP type and gross and fine motor skills for young adults with CP. They were trained to complete the expanded and revised Gross Motor Function Classification System (GMFCS)[25] and the Bimanual Fine Motor Function (BFMF[26] classification. Items classify functional ability from the highest level (level I) to the lowest (level V). Recent IQ results were asked but few were available (n = 6). To address this lack of information we used questionnaire completion status as a proxy measure of higher versus lower intellectual capacities. We distinguished between self-respondents without assistance, self-respondents with assistance, and proxy respondents. The concurrent validity of this measure was assessed by correlation between questionnaire completion status and intellectual impairment using longitudinal data for the 145 participants in SPARCLE 3 who had already participated in SPARCLE 2 (Table 1).

2.3. Statistical analyses

Five participation domains were analyzed separately. Structural equation modeling (SEM) was used (Appendix A3).

First, we compared the participation of young adults with CP with that of their non-CP peers using a model explaining latent participation scores by CP status, adjusted for identified confounders in the non-CP population. As Kline explained[27(p21)], the β coefficient can be considered as an estimate of the difference on the latent scale. Here, we used this principle to estimate differences in participation between young adults with CP and their non-CP peers.

Secondly, the mediating roles of contextual characteristics, financial difficulties and student status were tested separately. The underlying assumption was that these characteristics form part of the causal chain between living with CP (CP status = 1) and levels of participation. From earlier models identified previously, a pathway between CP status and the contextual factor was added. Mediation was determined according to three conditions: CP status has an effect on the mediator M, M has an effect on participation, and either CP status has an effect on participation (a partial mediation) or CP status shows a zero-effect on participation (full mediation).

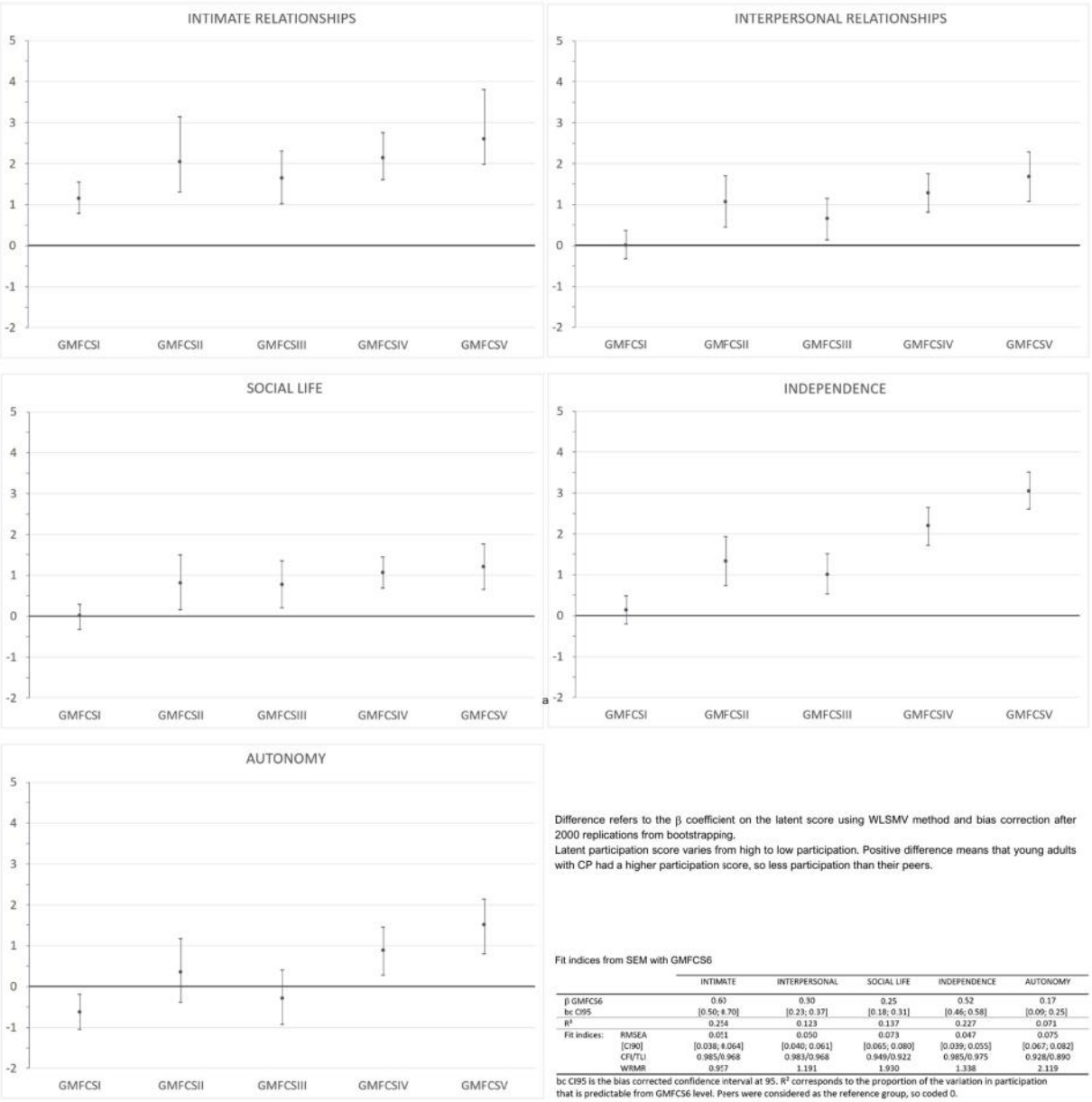
Thirdly, we tested the moderating roles of personal characteristics: sex, age, country of residence, population size of area of residence, and parental level of education. Moderators are variables that positively or negatively influence the difference in participation. Interaction analyses were therefore conducted.

Lastly, we tested the effect of impairment severity on participation. Gross motor function, fine motor skills and questionnaire completion status were tested separately. Non-CP peers were considered as the reference group, coded 0 on the impairment scales.

95 % confidence intervals were reported using a bias-corrected bootstrap procedure [bcCI95][28] with 2000 replications. As recommended by Hooper,[29] the Chi-Square statistic, its degrees of freedom (df) and pvalue, the Root Mean Square Error of Approximation (RMSEA), the Comparative Fit Index (CFI) and the Weighted Root Mean square Residual (WRMR) were reported. Goodness of fit was considered acceptable if RMSEA <0.10, CFI >0.80; and good if RMSEA <0.05, CFI >0.95. Data were analyzed using Stata 14.2 and Mplus 6.1.

3. Results

A total of 228 young adults with CP and 2861 peers were included in this study (Table 2). Significant differences between the two populations were observed for country, population size of area of residence, financial difficulties and student status. Young people with CP had various types of CP, with all levels of impairment.



		INTIMATE	INTERPERSONAL	SOCIAL LIFE	INDEPENDENCE	AUTONOMY
β GMFCS6		0.63	0.30	0.25	0.52	0.17
bc CI95		[0.50; 4.70]	[0.23; 0.37]	[0.18; 0.31]	[0.46; 0.58]	[0.09; 0.25]
R^2		0.254	0.123	0.137	0.227	0.071
Fit indices:	RMSEA	0.051	0.050	0.073	0.047	0.075
	[CI90]	[0.038; 4.064]	[0.040; 0.061]	[0.065; 0.080]	[0.039; 0.055]	[0.067; 0.082]
	CFI/TLI	0.985/0.968	0.983/0.968	0.949/0.922	0.985/0.975	0.928/0.890
	WRMR	0.957	1.191	1.930	1.338	2.119

bc CI95 is the bias corrected confidence interval at 95. R^2 corresponds to the proportion of the variation in participation that is predictable from GMFCS6 level. Peers were considered as the reference group, so coded 0.

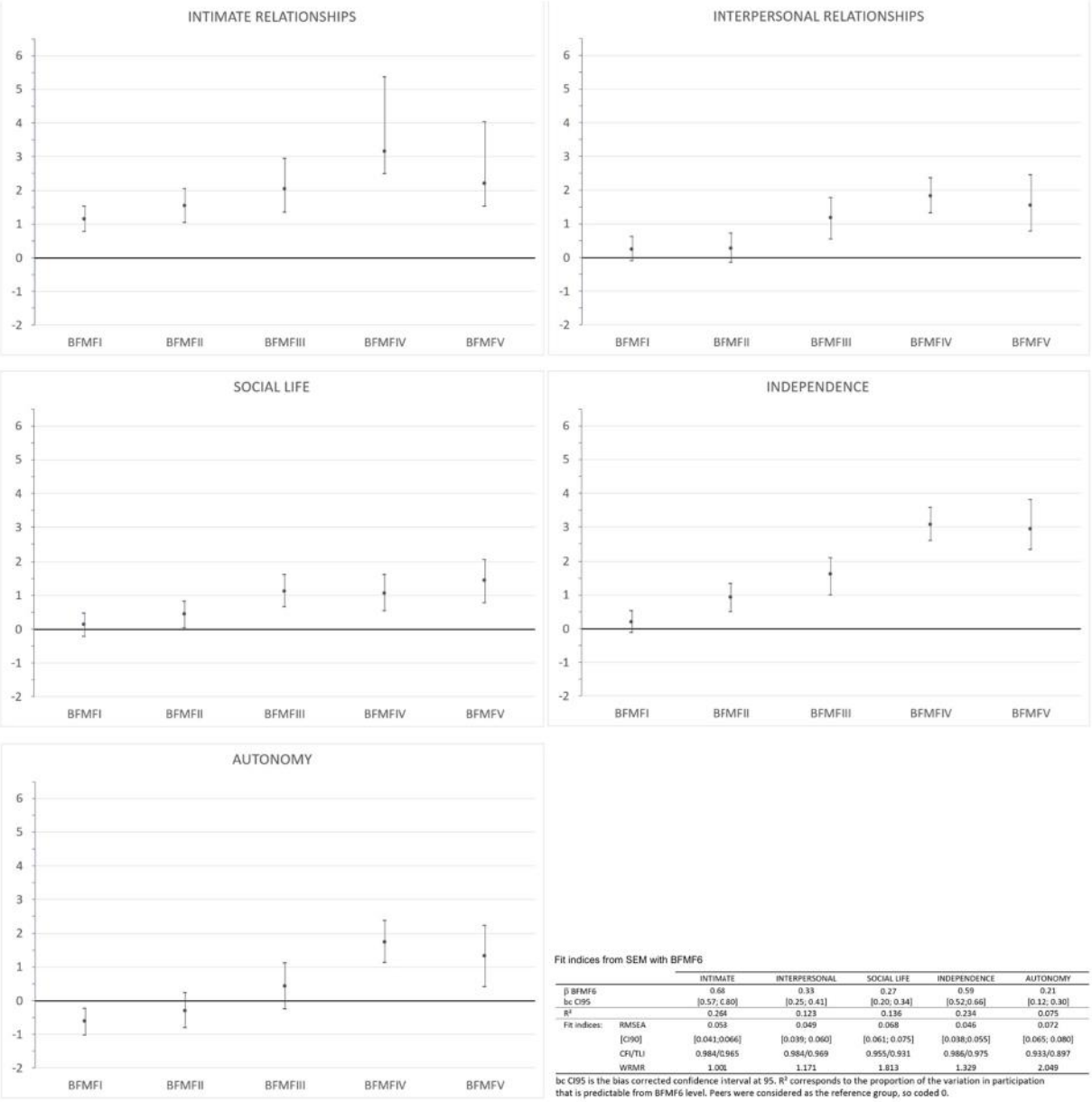
Fig. 3. Participation differences between young adults with CP and their non-CP peers (reference) by subgroup of impairments, and bias-corrected bootstrap confidence intervals.
Difference refers to the β coefficient on the latent score using the weighted least squares with mean and variance adjusted (WLSMV) method and bias correction after 2000 replications from bootstrapping. Latent participation score ranges from high to low participation. Positive difference means that young adults with CP had a higher participation score, so less participation than their peers.

3.1. Lower participation in each domain in young people with CP

Fig. 2 depicts the latent structural models explaining participation in five domains according to CP status and significant confounders (list in Appendix Table A1). These models showed acceptable to good fit indices. In all domains, participation differences, estimated by the β coefficients of CP status on latent participation, were significant and positive: participation was lower in young adults with CP than in their non-CP peers. The "intimate relationships" and "independence" domains showed the largest differences (β = 1.71 bcCI95[1.46; 1.95] and β = 1.24 bcCI95[1.02; 1.24], respectively).

3.2. Mediating effects of contextual characteristics

Total effects are presented in Table 3. Financial difficulties did not mediate the effect of CP status on any participation domain, all else being equal. Student status appeared to mediate the effect of CP status on participation in "intimate relationships", "interpersonal relationships" and "independence". We observed three significant effects between CP status, student status and participation latent scales, all else being equal: students expressed less participation in "intimate relationships" than non-students (β = 0,29 bcCI95[0,17; 0,41]); young people with CP were less likely to be students than their peers (β = −0,09 bcCI95[−0,14; −0,04]); and living with CP was associated with less participation in "intimate relationships" than their peers (β = 1,71 bcCI95[1,46; 1,96]). The lower proportion of students among young



Fit indices from SEM with BFMF6

		INTIMATE	INTERPERSONAL	SOCIAL LIFE	INDEPENDENCE	AUTONOMY
β BFMF6		0.68	0.33	0.27	0.59	0.21
bc CI95		[0.57; 0.80]	[0.25; 0.41]	[0.20; 0.34]	[0.52;0.66]	[0.12; 0.30]
R^2		0.264	0.123	0.136	0.234	0.075
Fit indices:	RMSEA	0.053	0.049	0.068	0.046	0.072
	[CI90]	[0.041;0.066]	[0.039; 0.060]	[0.061; 0.075]	[0.038;0.055]	[0.065; 0.080]
	CFI/TLI	0.984/0.965	0.984/0.969	0.955/0.931	0.986/0.975	0.933/0.897
	WRMR	1.001	1.171	1.813	1.329	2.049

bc CI95 is the bias corrected confidence interval at 95. R^2 corresponds to the proportion of the variation in participation that is predictable from BFMF6 level. Peers were considered as the reference group, so coded 0.

Fig. 3. (*continued*).

people with CP could therefore lead to an underestimation of the difference in participation in this domain. Due to the significant negative effect of student status on participation in the domains of "interpersonal relationships" and "independence", the total effects of CP status on participation were increased by the mediating effect of student status.

3.3. Sex as a moderator of the difference in "independence"

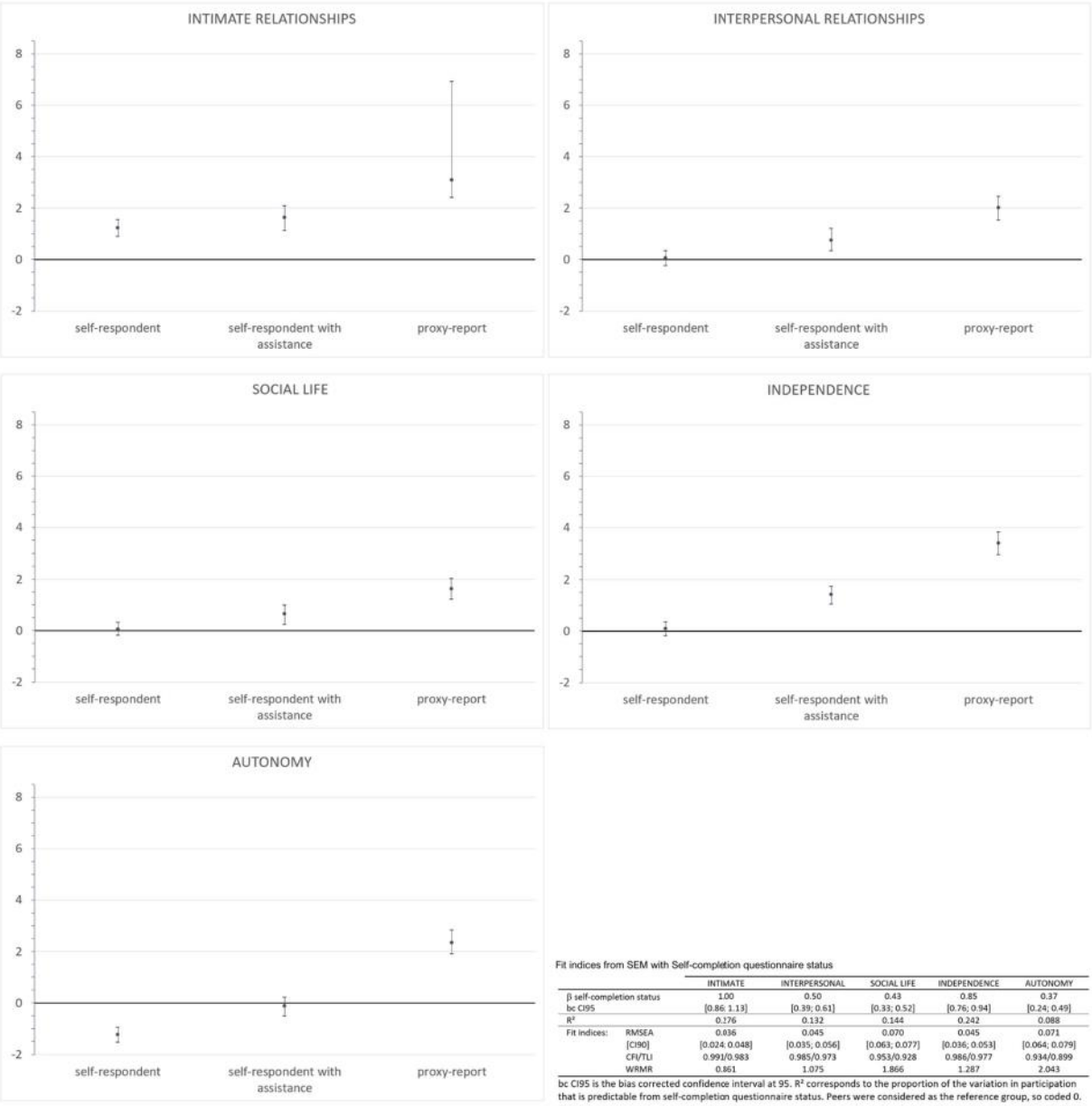
Testing for five personal factors as moderators of participation in the five domains of participation showed that only sex significantly moderated "independence". This model showed good fit indices ($\chi^2 = 84.54$ df = 16 $p < 0.001$; RMSEA = 0.038; CFI = 0.988; WRMR = 1.139). Subgroup analysis showed a significantly greater difference from non-CP peers in women (β = 1.49 bcCI95[1.14; 1.81]) than in men (β = 1 0.04 bcCI95[0.76; 1.31]).

3.4. Wider differences among the most severely impaired

SEM showed significant effects of GMFCS, BFMF and questionnaire completion status on latent participation. Fig. 3 shows the differences in subgroup analyses as well as the reported fit indices from SEM. Of the three types of impairment, questionnaire completion status had the largest effect on "intimate relationships" (β = 1.00 bcCI95[0.86; 1.13]). There were no significant differences between young adults with CP and the lowest level of impairment compared to their non-CP peers in the domains of "interpersonal relationships", "social life" and "independence". The difference in participation between these two groups in "autonomy" was significantly negative, showing that young adults with the lowest level of impairment made more autonomous decisions in daily life than their non-disabled peers.

4. Discussion

Over the past decade, participation has emerged as an important outcome for disability research. Countries committed to respecting the rights of people with disabilities aim to enable them to participate fully in society on an equal basis with others. Estimating the participation gap between people with and without disability serves to show how far we



Fit indices from SEM with Self-completion questionnaire status

		INTIMATE	INTERPERSONAL	SOCIAL LIFE	INDEPENDENCE	AUTONOMY
β self-completion status		1.00	0.50	0.43	0.85	0.37
bc CI95		[0.86; 1.13]	[0.39; 0.61]	[0.33; 0.52]	[0.76; 0.94]	[0.24; 0.49]
R^2		0.176	0.132	0.144	0.242	0.088
Fit indices:	RMSEA	0.036	0.045	0.070	0.045	0.071
	[CI90]	[0.024; 0.048]	[0.035; 0.056]	[0.063; 0.077]	[0.036; 0.053]	[0.064; 0.079]
	CFI/TLI	0.991/0.983	0.985/0.973	0.953/0.928	0.986/0.977	0.934/0.899
	WRMR	0.861	1.075	1.866	1.287	2.043

bc CI95 is the bias corrected confidence interval at 95. R^2 corresponds to the proportion of the variation in participation that is predictable from self-completion questionnaire status. Peers were considered as the reference group, so coded 0.

Fig. 3. (*continued*).

are from achieving equality. The primary objective of this study was to estimate this gap among young emerging adults. We observed significant unfavourable differences for young adults with CP in five major domains of participation.

Previous studies conducted during childhood and adolescence have also reported disadvantages, except in specific areas such as playing electronic games.[16] Our results confirm those of Wiegerink et al.[5] that young adults with CP have fewer intimate relationships than their non-CP peers. According to these authors,[5] young adults with CP may be subjected to parental overprotection, lack sexual maturity, or have fewer opportunities for contact with their peers. The qualitative study conducted to develop the QYPP-YA[24] underlied the difficulties of meeting a partner, particularly for young persons with more severe disability needing assistance. For Friedman,[30] they may suffer from a lack of intimacy due to their housing arrangements and the number of housemates, as well as from a general negative attitude towards their sexuality of family members and professionals. Michelsen[16] showed that adolescent with CP had less time alone with their friends without adult supervision and less of time with boy/girlfriends.

Another finding of this study is the mediating effect of schooling on differences in participation. Education can develop independence in life choices and interpersonal relationships. This result is in line with the work of Wiegerink et al.[5] and supports the positive effect of mixed peer contacts. Nonetheless, our cross-sectional study could not demonstrate the causal relationship between continuance in education and participation in independence or interpersonal relationships. On the other hand, we observed that education mediates the participation difference in the domain of "intimate relationships". The small number of young people with CP still continuing education between 19 and 28 reduced the participation gap with their non-CP peers. These young people showed less severe intellectual and physical impairments. In their analysis of lifespan development, Wood et al.[31] described young adulthood as a period of emergence influenced by numerous changes. These changes affect independence in life and in decision-making, social and intimate relationships and educational achievement. According to this theoretical framework, these factors act interdependently on youth development. In any event, the pursuit of education is essential for better professional opportunities and social development. It should be

encouraged for young people with CP. Going further, society must invest in truly inclusive education, equal opportunity and individualized education systems for young adults with disabilities.[16]

Our study also confirmed that differences in participation increased with the severity of impairment. It was already known that the severity of impairment increased the difference in participation between people with and without disabilities.[16] Interestingly, we observed that less severely impaired young adults with CP showed no difference with their non-CP peers in "interpersonal relationships", "social life" and "independence". However, the gap between young people with CP and their non-CP peers remains wide in "intimate relationships", even at the lowest level of impairment. We also found a singularity in the domain of autonomy: the young adults with CP who were the least severely impaired were more likely than their non-CP peers to make autonomous decisions in daily life. Possibly, these young adults with the lowest level of impairment had themselves encountered many difficulties, becoming resourceful as a result. As Wood et al.[31] pointed out, overcoming challenges leads to a positive developmental trajectory.

Far from the aspirations of young people with CP described in a qualitative study by Hanes et al.,[32] we found that young people were not as free to choose their school and profession and did not enjoy as much freedom of movement as their non-CP peers. This lack of independence is even more prononced for young women with CP. Young women with disabilities face discrimination both as women and as people with a disability.[33] Professionals should be aware of this discrimination and shoud be trained to alleviate it.

4.1. Limitations

This study has some limitations. Data collection differed in method for the two samples, with unbalanced sample sizes. To compensate for this, we used the bootstrap method and presented a bias-corrected bootstrap confidence interval, which produced robust results.

We included people requiring assistance and proxy respondents in this study to enable those with low intellectual capacity to participate. Their responses could be biaised by the presence of their parents. Nevertheless, the subgroup analyses reported here followed the course of subgroup analyses for walking and grasping impairments, supporting the assumption of largest differences in young people with severe impairments.

Another limitation of this study is the low variance of latent participation explained by these models. This suggests that we overlooked a number of influential factors. As described in the ICF, capacity and attendance are strongly related and are influenced by body function as well as by personal and environmental factors. Future studies should consider introducing the young adult's capacity into an overall model explaining participation in terms of both attendance and involvement, together with body function, personal and environmental factors.

Due to study design, we were unable to analyze online communication. This is, however, an important domain,[34] and particularly for people with severe physical disabilities.[34] Such persons can face financial barriers, difficulty in using devices and platform accessibility.[20] These issues remain to be explored.

5. Conclusions

We observed a large participation gap between young adults with CP and those without disabilities, moderated primarily by severity of impairment. Young adults with CP do not have the same opportunities to achieve the levels of participation of non-disabled peers. Special attention should be paid to young women, who are less likely to make independent life choices. Young people with more severe impairments need to be more fully integrated into society. Continuance of education could help to reduce participation difference in "interpersonal relationships" and "independence". Policymakers should provide a supportive and reassuring school environment enabling educational achievement for all young people with and without disabilities.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2023.101554.

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Unmet environmental needs and unmet healthcare needs in a population of young adults with cerebral palsy: what the SPARCLE study tells us

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Introduction: Optimizing care for young adults with cerebral palsy is crucial for their physical and psychological well-being. The inadequacy of proximal environment may play a role in the provision of health services. The aim of this study is to explore the association between unmet environmental needs in the physical, social and attitudinal domains and unmet healthcare needs in four interventions: physiotherapy, occupational therapy, speech therapy and psychological counselling.

Methods: Young adults with cerebral palsy were recruited in the SPARCLE3 European multicenter cross-sectional study. Healthcare needs and coverages were assessed using the Youth Health Care, Satisfaction, Utilization and Needs questionnaire. The need and availability of environmental factors in physical, social and attitudinal domains were collected using the European Adult Environment Questionnaire. Logistic regressions were conducted separately for each intervention to measure associations between unmet environmental needs and unmet healthcare needs.

Results: We studied 310 young adults with cerebral palsy, with a mean age of 24.3 years; 37.4% could not walk independently, 51.5% had an IQ below 70, 34.2% had severe communication difficulties. The most commonly expressed need was physiotherapy (81.6% of participants). Unmet healthcare needs were reported by 20.9%, 32.4%, 40.3% and 49.0% of participants requiring physiotherapy, occupational therapy, psychological counselling and speech therapy, respectively. The physical environment was never significantly associated with unmet healthcare needs. In contrast, the social environment was significantly associated with unmet healthcare needs across all interventions, with odds ratios over 2.5, depending on the number of unmet needs and the nature of intervention needed. With regard to the attitudinal environment, when at least one unmet attitudinal environmental need was reported, the odds of also reporting an unmet healthcare need were of 3.68 for speech therapy and 3.77 for physiotherapy. The latter association was significant only for individuals with severe motor impairment.

Abbreviations

CI, confidence interval; CP, Cerebral palsy; EAEQ, European Adult Environment Questionnaire; EF, environmental factors; FCCS, Functional Communication Classification System; GMFCS, Gross Motor Function Classification System; ICF, International Classification of Functioning, Disability and Health; IQ, intelligence quotient; OR, odds ratio; SCPE, Surveillance of Cerebral Palsy in Europe network; SPARCLE, Study of PARticipation of children with Cerebral palsy Living in Europe; YHC-SUN, Youth Health Care, Satisfaction, Utilization and Needs; WHO, World Health Organization.

Discussion: Our results highlight the importance of the social and attitudinal environment in meeting healthcare needs in young adults with cerebral palsy. The lack of correlation between unmet healthcare needs and the physical environment suggests that it can be partly compensated for by social support.

KEYWORDS

cerebral palsy, unmet healthcare needs, environmental needs, impairments, young adults

Introduction

The 2006 United Nations Convention on the Rights of Persons with Disabilities (1) underlines the obligation of Member States to take appropriate measures to ensure access for persons with disabilities to all aspects of life in order to promote their full participation in society on the basis of equal opportunities. Access to health services is one the major obstacles to equal opportunity for people with disabilities, particularly those with cerebral palsy.

Cerebral palsy (CP) is a complex condition that requires lifelong multidisciplinary care (2, 3). This care encompasses, among other things, access to specialized medical services, rehabilitation interventions, and psychological counselling. Optimizing and personalizing care is of paramount importance in meeting the specific needs of individuals with CP and maximizing their physical and psychological well-being (4). Medical advances have enabled individuals with CP to live longer, bringing their life expectancy closer to that of the general population (5). However, with improved survival come new health challenges. Young adults with CP face specific health issues, including a variety of clinical manifestations associated with CP (6) and early deterioration in health status (7). Compared with the general population, these young adults experience reduced walking ability, increased pain and fatigue, and mental health problems. It is therefore crucial to take account of these specific needs to provide them with appropriate care.

However, young adults with CP often have less access to health services in adulthood than they did in childhood (8) and face complex and varied barriers, such as a lack of specialized services tailored to adults or limited knowledge about adult CP among health professionals, that lead to gaps in continuity of care. As the International Classification of Functioning, Disability and Health (ICF) has defined disability since 2001 as resulting from a dynamic interaction between "body functions and structures" and "personal and environmental contextual factors", we should also consider the inadequacy of the environment as a potential barrier to accessing health services.

There is little in-depth research specifically examining the overall impact of the environment on access to care for young adults with CP. The majority of existing studies have focused mainly on the medical and clinical aspects of care (9, 10), paying less attention to environmental factors likely to influence access to care. However, in the case of chronic conditions such as CP, it is often easier to modify an individual's environment than their abilities or bodily functions (11). It is therefore crucial to understand the extent to which inadequate physical, social, and attitudinal environments are associated with access to care among these young adults. To do this, we used unmet health needs as an indicator, which allows us to capture participants' actual experiences of accessing healthcare.

We aimed to explore the association between unmet environmental needs and unmet healthcare needs by focusing on four types of intervention: physiotherapy, occupational therapy, speech therapy, and psychological counselling. We hypothesized that the accumulation of unmet needs in the environment is associated with compounded unmet needs in health domains in young adults with CP.

Methods

Design and population

We used data from SPARCLE3, a European multicenter observational population-based cross-sectional study designed to investigate the impact of the environment on participation and quality of life of young adults with CP. The design and methods of the study have been described elsewhere (12). Briefly, the study population consisted of young adults diagnosed with CP as defined by the Surveillance of Cerebral Palsy in Europe (SCPE) network (13). They were born between 1991 and 1997, and were aged between 22 and 27 years at the time of data collection (2018–2020). They were randomly selected from regional registries in France, Sweden and Italy, and recruited from various sources in two other regions in Germany and Portugal.

Data collection

Research assistants trained for the study visited the young adults with CP and conducted the interviews under identical conditions, with a logical flow and a fixed order for completing the questionnaires. Whenever possible, young adults completed the questionnaires themselves, with research assistants providing assistance as needed. When this was not possible, a relative or a personal assistant closely involved in their daily lives acted as a proxy.

Young adults with CP were asked about their healthcare needs, coverage and satisfaction of those needs, in various healthcare domains, using the short form of Youth Health Care, Satisfaction, Utilization and Needs (YHC-SUN) questionnaire (14). In this study, we considered only rehabilitation domains

(physiotherapy, occupational therapy, speech therapy) and psychological counselling.

Information regarding the physical, social and attitudinal environment was collected using the European Adult Environment Questionnaire (EAEQ), a questionnaire developed as part of SPARCLE3, were which assesses the adequacy of 61 environmental factors (EF). Content density, diversity ratios and bandwidth index indicate that the EAEQ content links fairly well to the environmental classification of the ICF Core Set for adults with CP (15). Two types of information were available: the need of the EF and its availability in the event of need, or only its availability when the need was considered *a priori* to be common to all individuals. The responses were categorized as "unmet environmental need" when the response "Needed and not available" was provided, and "met environmental need" when the responses "Not needed" or "Needed and available" were ticked, depending on the item. In each domain of the environment, items related to access to care were selected *a priori* (9, 4 and 3 items in the physical, social, attitudinal domains, respectively, Supplementary Table S1).

Standardized information on impairments and comorbidities was collected: walking ability (using the Gross Motor Function Classification System, GMFCS (16) levels grouped into walkers (GMFCS I–III) and non-walkers (GMFCS IV–V)) and communication performance (Functional Communication Classification System, FCCS) (17), effective communication Yes (FCCS I–II)/No (FCCS III–V)). Intellectual ability was assessed with formal IQ testing or using an algorithm based on a set of questions to proxies (18), and thereafter categorized as <70/≥70. Young adults also reported their pain over the past week (not at all/once or twice/frequent) and seizures in the year predating interview [No (with or without medication)/Yes].

We also collected personal and family contextual factors: population size of area of residence (>200,000/3,000–200,000/ <3,000 inhabitants), lifestyle [living alone independently/ accompanied (family/partner)/ in care facilities], personal and parental highest education level completed (did not complete secondary education/secondary education/tertiary education), and perceived wealth (no or minimal financial difficulties/ financial difficulties).

Statistical analyses

Four subgroups of people were identified according to the health needs they reported to require for physiotherapy, occupational therapy, speech therapy, or psychological counselling (19). We first described the distribution of impairments, comorbidities, and contextual factors in the whole sample and in subgroups. The proportion of young adults who reported unmet environmental needs was estimated in the same subgroups. In addition, for each environmental domain, we plotted the proportion of individuals with unmet health needs against the number of unmet environmental needs (discrete variable) to determine categories, considering individuals with no unmet needs as the reference class, and a minimum of five individuals in each category.

Thereafter, separate analyses were carried out for physiotherapy, occupational therapy, speech therapy, and psychological counselling subgroups to assess the role of environmental factors on the satisfaction of healthcare needs. Bivariate comparisons relating the proportion of individuals with unmet health needs to socio-demographic and impairments characteristics were carried out. We then performed logistic regressions to estimate odds ratios (ORs) and their 95% confidence intervals (95% CI) which measured associations between unmet environmental needs in each domain and unmet physiotherapy/occupational therapy/speech therapy/psychological counselling need. All models were adjusted for country due to the recruitment (20) and policies for people with disabilities diversity across countries, and sex (21). Model 1 was consistently adjusted for GMFCS (22) and Model 2 for the size of the unit of residence and lifestyle (10, 23), as these were described in the literature as potential confounders. To identify potential additional confounding factors, two successive stepwise selections were then performed: the first added clinical variables (intellectual ability, seizures communication performance and frequency of pain) to Models 1, while the second included sociodemographic variables (education, wealth, and parental highest education level) in addition to Models 2, with the aim of minimizing the number of variables introduced into the models. Multivariate models were used to control for significant variables in separate analyses ($p < 0.20$) and these models were reduced using a descending step-by-step method with $p < 0.05$ as criterion for statistical significance. Participants with missing data for one or more variables in the different models were few, and they were excluded from the analyses.

Finally, sensitivity analyses were conducted. First, we considered only individuals who self-completed the questionnaires. Second, to examine the impact of each country on the results, with constraints of the small sample sizes, we excluded participants from each country one by one.

All analyses were performed using R (version 4.1.2, R Core Team, 2021).

Results

Our sample consisted of 310 young adults with CP, with a mean age of 24.3 years [standard deviation (SD) 1.6 years], and a male-to-female ratio of 1.2. Table 1 shows impairments and socio-demographic characteristics. Briefly, 37.4% of individuals could not walk independently (GMFCS IV–V), 51.5% had an IQ < 70, and 34.2% had severe communication difficulties (FCCS III-V). Around 12% (11.7%) lived alone. In terms of healthcare needs, physiotherapy was the most frequently mentioned (81.6% of participants), followed by occupational therapy (47.7%), psychological counselling (40.0%), and speech therapy (31.6%). Of the participants who reported all rehabilitation needs (physiotherapy, speech therapy and occupational therapy, $n = 72$), 56.9% had a GMFCS IV–V, 66.7% had a FCCS level III to V,

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TABLE 1 Characteristics of young adults with CP across the entire sample and by health needs subgroups.

	All participants (*n* = 310)		Physiotherapy need (*n* = 253)		Occupational therapy need (*n* = 148)		Speech therapy need (*n* = 98)		Psychological counselling need (*n* = 124)	
Sex										
Male	171	55.2	133	52.6	79	53.4	54	55.1	69	55.6
Female	139	44.8	120	47.4	69	46.6	44	44.9	55	44.4
Age (years)										
22	52	16.8	46	18.2	23	15.5	21	21.4	20	16.1
23	54	17.4	42	16.6	32	21.6	18	18.4	26	21.0
24	66	21.3	57	22.5	37	25.0	23	23.5	26	21.0
25	64	20.6	47	18.6	27	18.2	21	21.4	23	18.5
26	42	13.5	35	13.8	13	8.8	10	10.2	16	12.9
27	32	10.3	26	10.3	16	10.8	5	05.1	13	10.5
Means (SD)	24.3	(1.57)	24.2	(1.58)	24.2	(1.53)	24.0	(1.46)	24.2	(1.57)
Impairment characteristics	N	%	n	%	n	%	n	%	n	%
GMFCS										
I–II–III	194	62.6	142	56.1	71	48.0	45	45.9	83	66.9
IV–V	116	37.4	111	43.9	77	52.0	53	54.1	41	33.1
Intellectual impairment										
≥70	127	48.5	94	44.3	43	33.3	12	15.0	54	48.6
<70	135	51.5	118	55.7	86	66.7	68	85.0	57	51.4
Seizures in the previous year										
No (with or without medication)	259	83.8	208	82.5	114	77.0	73	74.5	107	87.0
Seizures	50	16.2	44	17.5	34	23.0	25	25.5	16	13.0
FCCS										
I–II	204	65.8	159	62.8	71	48.0	38	38.8	83	66.9
III–IV–V	106	34.2	94	37.2	77	52.0	60	61.2	41	33.1
Frequency of pain in previous week										
None	108	35.0	78	31.1	49	33.3	36	36.7	35	28.2
Once or twice	129	41.7	57	22.7	61	41.5	37	37.8	51	41.1
Frequent	72	23.3	116	46.2	37	25.2	25	25.5	38	30.6
Sociodemographic characteristics	N	%	n	%	n	%	n	%	n	%
Country										
France	82	26.5	69	27.3	36	24.3	29	29.6	39	31.5
Sweden	29	09.4	23	09.1	23	15.5	12	12.2	11	08.9
Italy	23	07.4	20	07.9	15	10.1	9	09.2	14	11.3
Germany	78	25.2	70	27.7	29	19.6	26	26.5	22	17.7
Portugal	98	31.6	71	28.1	45	30.4	22	22.4	38	30.6
Size of unit of residence (inhabitants)										
>200,000	107	34.7	84	33.3	43	29.3	27	27.6	38	30.9
3,000–200,000	145	47.1	120	47.6	76	51.7	48	49.0	62	50.4
< 3,000	56	18.2	48	19.0	28	19.0	23	23.5	23	18.7

(*Continued*)

TABLE 1 Continued

	All participants ($n = 310$)		Physiotherapy need ($n = 253$)		Occupational therapy need ($n = 148$)		Speech therapy need ($n = 98$)		Psychological counselling need ($n = 124$)	
Lifestyle										
Living alone	36	11.7	31	12.3	12	08.2	4	04.1	20	16.1
Living accompanied	242	78.3	195	77.4	110	74.8	80	82.5	93	75.0
In care facilities	31	10.0	26	10.3	25	17.0	13	13.4	11	08.9
Education level										
Did not complete secondary education	177	58.0	150	60.5	94	65.3	72	75.0	73	60.3
Secondary education	83	27.2	62	25.0	40	27.8	20	20.8	32	26.4
Tertiary education	45	14.8	36	14.5	10	06.9	4	04.2	16	13.2
Parental education level										
Did not complete secondary education	110	36.1	90	36.1	52	35.9	36	37.1	43	35.2
Secondary education	101	33.1	84	33.7	46	31.7	31	32.0	39	32.0
Tertiary education	94	30.8	75	30.1	47	32.4	30	30.9	40	32.8
Wealth										
No or minimal financial difficulties	234	77.2	185	74.0	98	68.1	67	70.5	91	76.5
Financial difficulties	69	22.8	65	26.0	46	31.9	28	29.5	28	23.5

CP, cerebral palsy; SD, standard deviation; GMFCS, Gross Motor Function Classification System; FCCS, Fonctionnal Communication Classification System.

and a small proportion (4.2%) lived alone. Three quarters (75%) of those who reported a need for speech therapy, whether or not they expressed other needs, had not completed secondary education, compared with 58.0% in the total sample. The group of young adults who said they needed psychological counselling, alone or in combination with other needs, had less severe motor (33.1% with GMFCS IV–V) and cognitive (86.7% with an IQ < 70) impairments than the group as a whole. They were also more likely to live alone than participants as a whole (16.1%).

Table 2 shows the distribution of unmet environmental needs in the physical, social and attitudinal domains, for the whole sample and for each group that reported a healthcare need, while the responses for each EF are provided in Supplementary Table S2. The proportion of subjects reporting the highest number of unmet environmental needs per domain (4–9, 2–4 and 1–3 for the physical, social, attitudinal environments, respectively) is lowest for the social environment, overall and for each group of expressed healthcare needs. In the subgroup of individuals who reported requiring all three rehabilitation interventions, unmet needs were high: 73.2%, 38.9% and 40.8% of individuals with at least one unmet need in the physical, social, and attitudinal environments, respectively, compared to 62.1%, 27.3%, 32.7% for the same environmental domains in the whole sample. Individuals who reported a need for psychological counseling also had a higher prevalence of unmet environmental needs in all three domains compared to the whole population, with 66.9%, 32.3%, and 38.8% of individuals with at least one unmet need in each domain of environment.

The proportion of individuals who reported unmet healthcare needs was the lowest for physiotherapy (20.9%), followed by occupational therapy (32.4%), psychological counselling (40.3%), and speech therapy (49.0%). Table 3 shows to what extent the proportion of individuals with unmet healthcare needs varied according to nature and severity of impairments, country of residence and socio-demographic characteristics. We observed a lower proportion of people with unmet healthcare needs for all types of rehabilitation interventions in young adults with GMFCS IV–V compared to those with GMFCS I–III. Significant differences between countries were observed for physiotherapy unmet needs (from 7.1% of the participants in Germany to 31.0% in Portugal; $p = 0.004$) and occupational therapy unmet needs (from 4.1% in France to 44.4% in Portugal, $p = 0.010$).

Bivariate analyses showed an interaction between the severity of gross motor dysfunction and the attitudinal environment in participants who reported a need for physiotherapy. The corresponding models were therefore run separately for individuals with GMFCS IV–V and those with GMFCS I–III. All models were adjusted as follows. In the beginning, all models were adjusted for sex and country of residence. Of the impairments and/or comorbidities, only walking ability was included in Models 1 with the exception of participants requiring speech therapy, for whom communication performance was also retained. Models 2 incorporated these factors, along with retained sociodemographic characteristics, specifically the population size of their unit of residence and lifestyle, without the addition of any other characteristics. The physical

TABLE 2 Distribution of unmet needs in the three environmental domains within the total population and by healthcare needs subgroup.

	All participants ($n = 310$)		Physiotherapy need ($n = 253$)		Occupational therapy need ($n = 148$)		Speech therapy need ($n = 98$)		Psychological counselling need ($n = 124$)	
	N	%	*n*	%	*n*	%	*n*	%	*n*	%
Physical environment (9 items)										
0 unmet need	116	37.9	76	30.4	41	27.9	25	26.0	41	33.1
1–3 unmet needs	114	37.3	101	40.4	59	40.1	39	40.6	51	41.1
4–9 unmet needs	76	24.8	73	29.2	47	32.0	32	33.3	32	25.8
Social environment (4 items)										
0 unmet need	224	72.7	173	68.9	99	67.8	62	63.3	84	67.7
1 unmet need	68	22.1	62	24.7	38	26.0	29	29.6	30	24.2
2–4 unmet needs	16	05.2	16	06.4	9	06.2	7	07.1	10	08.1
Attitudinal environment (3 items)										
0 unmet need	204	67.3	165	66.5	90	61.6	59	61.5	74	61.2
1–3 unmet needs	99	32.7	83	33.5	56	38.4	37	38.5	47	38.8

environment was never significantly associated with unmet healthcare needs, regardless of the intervention. Conversely, the social environment was associated to varying degrees of unmet healthcare needs in all four interventions. When one unmet need for the social environmental was reported, the odds of also reporting an unmet need for physiotherapy increased more than twofold (OR 2.5; 95% CI: 1.18–5.55). When 2–4 unmet social environmental needs were reported, the odds of reporting unmet occupational therapy and psychological counselling needs were OR 6.58 (95% CI: 1.17–41.38) and 12.89 (95% CI: 2.14–120.91), respectively. A significant trend was observed for speech therapy. With regards to the attitudinal environment, when at least one unmet environmental need was reported, the odds of also reporting an unmet healthcare need increased more than three-fold for speech therapy (OR 3.68; 95% CI: 1.41–10.31) and for physiotherapy (OR 3.77; 95% CI: 1.22–12.80), the latter only in those with severe motor impairment (GMFCS IV–V) (Table 4).

The results did not change after excluding individuals with proxy-reports or excluding participants from each country one by one.

Discussion

Key findings

Our study showed that the commonest healthcare need was physiotherapy, which was reported by more than four out of five young adults with CP. Among those who expressed a need for care, the proportion whose need was not met varied according to the type of care required: 20.8%–48.5% for rehabilitation, and 40.3% for psychological counselling. We found an association between an environment inadequate to the specific needs of young people with CP and their care needs. More specifically, the accumulation of unmet needs in the social environment, exploring support from the personal assistant, family and friends, healthcare staff and colleagues, and strangers, was associated with unmet needs in all health domains explored, even taking account of the severity of impairments and the socio-demographic characteristics of the individuals. The lack of supportive attitudes increased by more than 3-fold the odds of also reporting an unmet need for speech therapy and physiotherapy, only among those with the most severely impaired gross motor function in the latter case. Finally, our study showed no association between unmet needs in the physical environment and unmet healthcare needs.

Strengths and limitations

This cross-sectional study enrolled 310 young adults with CP, making it one of the largest studies ever conducted in this population. We identified cases either from population-based registries or from several independent sources, using the same definition of CP, which limited case selection and classification errors. Nevertheless, recruitment in Germany and Portugal,

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TABLE 3 Distribution of healthcare needs met and unmet within the four subgroups of healthcare needs.

	Physiotherapy need ($n = 253$)					Occupational therapy need ($n = 148$)					Speech therapy need ($n = 98$)					Psychological counselling need ($n = 124$)				
	Met ($n = 200$)		Unmet ($n = 53$)			Met ($n = 100$)		Unmet ($n = 48$)			Met ($n = 50$)		Unmet ($n = 48$)			Met ($n = 74$)		Unmet ($n = 50$)		
	n	%	*n*	%	*p*	*n*	%	*n*	%	*p*	*n*	%	*n*	%	*p*	*n*	%	*n*	%	*p*
Sex					0.966					0.356					0.823					0.003
Male	105	78.9	28	21.1		56	70.9	23	29.1		27	50.0	27	50.0		33	47.8	36	52.2	
Female	95	79.2	25	20.8		44	63.8	25	36.2		23	52.3	21	47.7		41	74.5	14	25.5	
Age (years)					0.233					0.666					0.542					0.932
Means (SD)	24.2	(1.60)	24.5	(1.51)		24.1	(1.49)	24.2	(1.61)		23.9	(1.49)	24.0	(1.44)		24.2	(1.52)	24.2	(1.66)	
GMFCS					0.052					0.002					0.016					0.169
I–II–III	106	74.6	36	25.4		39	54.9	32	45.1		17	37.8	28	62.2		46	55.4	37	44.6	
IV–V	94	84.7	17	15.3		61	79.2	16	20.8		33	62.3	20	37.7		28	68.3	13	31.7	
Intellectual impairment					0.787					0.111					0.851					0.058
≥70	71	75.5	23	24.5		25	58.1	18	41.9		6	50.0	6	50.0		37	68.5	17	31.5	
<70	91	77.1	27	22.9		62	72.1	24	27.9		32	47.1	36	52.9		29	50.9	28	49.1	
Seizures in the previous year					0.108					0.991					0.082					0.150
No (with or without medication)	169	81.2	39	18.8		77	67.5	37	32.5		41	56.2	32	43.8		67	62.6	40	37.4	
Seizures	31	70.5	13	29.5		23	67.6	11	32.4		9	36.0	16	64.0		7	43.8	9	56.2	
FCCS					0.461					0.296					0.504					0.082
I–II	128	80.5	31	19.5		45	63.4	26	36.6		21	55.3	17	44.7		54	65.1	29	34.9	
III–IV–V	72	76.6	22	23.4		55	71.4	22	28.6		29	48.3	31	51.7		20	48.8	21	51.2	
Frequency of pain in previous week					0.553					0.479					0.416					0.036
None	60	75.0	20	25.0		30	61.2	19	38.8		17	47.2	19	52.8		16	45.7	19	54.3	
Once or twice	87	81.3	20	18.7		44	72.1	17	27.9		22	59.5	15	40.5		37	72.5	14	27.5	
Frequent	53	80.3	13	19.7		25	67.6	12	32.4		11	44.0	14	56.0		21	55.3	17	44.7	
Country					0.004					0.010					0.063					0.781
France	18	78.3	5	21.7		22	95.7	1	04.3		8	66.7	4	33.3		5	45.5	6	54.5	
Sweden	54	78.3	15	21.7		24	66.7	12	33.3		13	44.8	16	55.2		25	64.1	14	35.9	
Italy	14	70.0	6	30.0		10	66.7	5	33.3		2	22.2	7	77.8		8	57.1	6	42.9	
Germany	65	92.9	5	07.1		19	65.5	10	34.5		18	69.2	8	30.8		12	54.5	10	45.5	
Portugal	49	69.0	22	31.0		25	55.6	20	44.4		9	40.9	13	59.1		24	63.2	14	36.8	
Size of unit of residence (inhabitants)					0.444					0.629					0.601					0.479
>200,000	64	76.2	20	23.8		28	65.1	15	34.9		15	55.6	12	44.4		20	52.6	18	47.4	
3,000–200,000	94	78.3	26	21.7		50	65.8	26	34.2		22	45.8	26	54.2		40	64.5	22	35.5	
<3,000	41	85.4	7	14.6		21	75.0	7	25.0		13	56.5	10	43.5		13	56.5	10	43.5	
Lifestyle					0.776					0.862					0.535					0.219

(*Continued*)

TABLE 3 Continued

	Physiotherapy need (*n* = 253)					Occupational therapy need (*n* = 148)					Speech therapy need (*n* = 98)					Psychological counselling need (*n* = 124)				
	Met (*n* = 200)		Unmet (*n* = 53)			Met (*n* = 100)		Unmet (*n* = 48)			Met (*n* = 50)		Unmet (*n* = 48)			Met (*n* = 74)		Unmet (*n* = 50)		
	n	%	*n*	%	*p*	*n*	%	*n*	%	*p*	*n*	%	*n*	%	*p*	*n*	%	*n*	%	*p*
Living alone	23	74.2	8	25.8		8	66.7	4	33.3		1	25.0	3	75.0		10	50.0	10	50.0	
Living accompanied	155	79.5	40	20.5		73	66.4	37	33.6		42	52.5	38	47.5		55	59.1	38	40.9	
In care facilities	21	80.8	5	19.2		18	72.0	7	28.0		6	46.2	7	53.8		9	81.8	2	18.2	
Education level					0.128					0.917					0.149					0.916
Did not complete secondary education	123	82.0	27	18.0		62	66.0	32	34.0		34	47.2	38	52.8		43	58.9	30	41.1	
Secondary education	49	79.0	13	21.0		28	70.0	12	30.0		11	55.0	9	45.0		18	56.2	14	43.8	
Tertiary education	24	66.7	12	33.3		7	70.0	3	30.0		4	100	0	00.0		10	62.5	6	37.5	
Parental education level					0.219					0.520					0.084					0.595
Did not complete secondary education	70	77.8	20	22.2		32	61.5	20	38.5		15	41.7	21	58.3		25	58.1	18	41.9	
Secondary education	71	84.5	13	15.5		31	67.4	15	32.6		21	67.7	10	32.3		21	53.8	18	46.2	
Tertiary education	55	73.3	20	26.7		34	72.3	13	27.7		14	46.7	16	53.3		26	65.0	14	35.0	
Wealth					0.599					0.996					0.483					0.278
No or minimal financial difficulties	148	80.0	37	20.0		66	67.3	32	32.7		33	49.3	34	50.7		56	61.5	35	38.5	
Financial difficulties	50	76.9	15	23.1		31	67.4	15	32.6		16	57.1	12	42.9		14	50.0	14	50.0	

SD, standard deviation; GMFCS, Gross Motor Function Classification System; FCCS, Fonctionnal Communication Classification System.

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TABLE 4 Association between the adequacy of EF and unmet health needs in the 4 domains.

	Unmet physiotherapy need ($n = 253$)					Unmet occupational therapy need ($n = 148$)					Unmet speech therapy need ($n = 98$)					Unmet psychological counselling need ($n = 124$)				
		Model 1[a]		Model 2[b]			Model 1[a]		Model 2[b]			Model 1[a]		Model 2[b]			Model 1[c]		Model 2[d]	
EF (unmet needs)	*n*	OR	95% CI	OR	95% CI	*n*	OR	95% CI	OR	95% CI	*n*	OR	95% CI	OR	95% CI	*n*	OR	95% CI	OR	95% CI
Physical																				
0	75	1.00		1.00		41	1.00		1.00		25	1.00		1.00		41	1.00		1.00	
1–3	101	0.48	(0.21–1.07)	0.50	(0.22–1.11)	59	0.49	(0.19–1.25)	0.53	(0.19–1.41)	39	0.80	(0.25–2.54)	0.82	(0.25–2.68)	51	0.71	(0.26–1.96)	0.89	(0.31–2.54)
4–9	72	0.92	(0.37–2.31)	0.89	(0.35–2.25)	45	0.57	(0.19–1.72)	0.54	(0.17–1.66)	31	2.05	(0.52–8.73)	1.95	(0.47–8.63)	31	1.50	(0.42–5.57)	1.77	(0.46–7.16)
Social																				
0	172	1.00		1.00		98	1.00		1.00		62	01.00		1.00		83	01.00		01.00	
1	62	2.64	(1.24–5.69)[†]	2.55	(1.18–5.55)[†]	38	2.50	(0.99–6.68)	2.52	(0.98–6.83)	29	04.23	(1.40–14.48)[†]	4.07	(1.32–14.09)[†]	30	01.88	(0.68–5.38)	02.08	(0.71–6.39)
2–4	15	2.59	(0.64–9.09)	2.95	(0.71–10.59)	8	6.09	(1.10–36.86)[†]	6.58	(1.17–41.38)[†]	6	12.10	(1.58–255.71)[†]	9.91	(1.22–214.86)[†]	10	13.58	(2.39–120.41)[†]	12.89	(2.14–120.91)[†]
Attitudinal (all individuals)																				
0						88	1.00		1.00		58	1.00		1.00		73	1.00		1.00	
1–3						56	1.41	(0.64–3.10)	1.28	(0.57–2.88)	37	3.25	(1.30–8.62)[†]	3.68	(1.41–10.31)[†]	47	0.82	(0.35–1.89)	0,94	(0.39–2.28)
Attitudinal (GMFCS I–II–III)																				
0	99	1.00		1.00																
1–3	40	0.58	(0.21–1.51)	0.54	(0.19–1.45)															
Attitudinal (GMFCS IV–V)																				
0	64	1.00		1.00																
1–3	43	3.84	(1.27–12.88)[†]	3.77	(1.22–12.80)[†]															

EF, environmental factors; GMFCS, Gross Motor Functional Classification System.
[a]adjusted for country, sex and GMFCS.
[b]adjusted for country, sex, GMFCS and sociodemographic characteristics (size of unit of residence and lifestyle).
[c]adjusted for country, sex, GMFCS and FCCS.
[d]adjusted for country, sex, GMFCS, FCCS and sociodemographic characteristics (size of unit of residence and lifestyle).
[†]95% CI excluding one.

although based on a variety of sources, included rehabilitation centres, hospitals and specialized institutes, which may first result in a lack of sample representativeness, and reduce the proportion of individuals with unmet healthcare needs. It was important to take this potential selection bias into account, given that participants from these two countries represented more than half of our sample (56.8%).

We performed the analyses by pooling self-reported and proxy-reported data to maximize the inclusion in the study of severely impaired people who are not usually included in this type of studies. Although we considered that, irrespective of the respondent, self-report was the best available estimate of environmental adequacy and unmet healthcare needs, we cannot rule out underestimation or overestimation of both these pieces of information when using proxy-reports (24, 25). Nevertheless, our findings did not change when we excluded proxy-reports in our sensitivity analyses.

The measurement of the adequacy of the environment to the specific needs of the target population was based on the EAEQ, a questionnaire developed as part of the SPARCLE study to provide a comprehensive assessment in line with the ICF. As part of this exploratory study, we made choices that respected the contours of this approach. First, we selected EAEQ items in the physical (accessibility of facilities and transport), social and attitudinal environment that were important for access to care. Based on the assumption that the accumulation of unmet needs in the environment was associated with unmet healthcare needs, we summed the items in each environmental domain to create one variable by domain quantifying environmental adequacy. However, due to the low prevalence of unmet needs for some elements of the environment and the lack of existing studies to guide us in our grouping choices, we opted for a graphical categorization. This choice enabled to obtain a sufficient number of individuals per category (at least five), except for the attitudinal domain, which limited the analysis of a potential cumulative effect. Another limitation was that this method assigned the same weight to each EF, which may potentially minimize or maximize their relative contribution (26).

Interpretation

To date, relatively little research has explored the healthcare needs of young adults with CP, focusing more on the utilization of healthcare services. A literature review by Manikandan et al. (21) of 57 studies involving 14,300 adults (mean age 18–48 years) found that 44% had consulted a physiotherapist, 27% an occupational therapist, 16% a speech therapist, and 11% a psychologist or psychiatrist in the past year. Although we did not have a direct measure of health service use, we observed similar frequencies when looking at the proportion of met healthcare needs for occupational therapy and speech therapy (32%; $n = 100/310$% and 16%; $n = 50/310$, respectively), while it was higher for physiotherapy (65%; $n = 200/310$) and psychological counselling (24%; $n = 74/310$). The high proportion of participants from Germany, where the number of physiotherapists is relatively high (244 physical therapists per 100,000 inhabitants (27) compared with 144 per 100,000 in France (28), for instance) may partly explain this difference.

While the utilization of health services is an important piece of information, measuring the need for these services and assessing how often they are not met are crucial in studying the factors limiting access. We found that, in descending order of frequency, the health care needs expressed were 81.6% for physiotherapy, 47.7% for occupational therapy, 40.0% for psychological counselling and 31.6% for speech therapy. To our knowledge, no recent study has comparable data. A cross-sectional study in Ireland of 40 young people aged 16–22 in transition to adult services found that 67.5% expressed healthcare needs related to mobility (which may partly correlate with physiotherapy), 50% related to positioning (which may partly correlate with occupational therapy), and 26.3% related to speech (likely correlated with speech therapy) (29). Another Anglo-Irish study of 106 14–18 year olds found similar results, with 58.4% of needs related to mobility, 25.5% to positioning, and 21.7% to speech (24).

In the literature, speech therapy has been described as the profession with the highest proportion of unmet needs, ranging from 39% to 70% (24, 29). Conversely, physiotherapy had the lowest proportion (12%–44%) (24, 29). Our results are consistent with these observations. In our study, severe motor impairment (GMFCS IV–V) was associated with better satisfaction of healthcare needs in the four professions, which differs from the data in the literature (9, 24) which showed that the severity of the disability tended to limit access to rehabilitation and psychological counselling. With regard to socio-demographic factors, an American study showed that adult men with disabilities were less likely than women to report at least one unmet healthcare need (60.7% vs. 75.7%) (30). However, we did not find this in our sample, and even found the opposite result for psychological counselling. A French study showed that living in care facilities was associated with a reduction in unmet healthcare needs (23), which was not observed in our study.

To our best knowledge, no publication has specifically evaluated the relationship between unmet healthcare needs of young adults with CP and the adequacy of their environment to meet their specific needs. Therefore, our interpretations are based solely on the results of our study, and we only have the opportunity to put forward a few hypotheses to explain this relationship. Our results highlight the importance of the social environment and support. At this age, greater independence and emancipation, particularly from parents, could partially explain why young adults have greater unmet healthcare needs than children. It may be hypothesized that the lack of association between the physical environment and unmet healthcare needs is due to the fact that the physical environment is often compensated by social support and assistance from family and friends. Thus, a young adult could move around easily if accompanied, even in a less suitable environment, whereas an individual with less support would have more difficulty even in a better adapted physical environment. It is also conceivable that this difference might be liked to cognitive impairments, which often pose more challenges for independent mobility than motor

impairments, for which adaptations are usually possible. Our findings suggest that the greater the unmet needs in the social environment, the greater the unmet healthcare needs for occupational therapy, speech therapy, and psychological counselling. However, due to the small number of participants with multiple unmet needs in their social environment, questions arise regarding these concepts, their content, and their implications for access to care for individuals with CP. Consequently, these findings should be interpreted with caution. Our findings indicated that attitudinal support was associated with unmet healthcare needs for speech therapy, which affects most people with severe motor and cognitive impairments, and for physiotherapy in people with severe motor impairments. This suggests that this support is particularly crucial to ensure access to healthcare for these therapies in severely impaired young adults with CP. We did not find this association in individuals who required occupational therapy or psychological counselling.

Conclusion

Our study showed that the adequacy of the environment, both social and attitudinal, can have an impact on unmet healthcare needs in different therapeutic areas in young adults with CP. It sheds valuable light on the factors influencing unmet health needs in this population. However, further research is needed to better understand and delineate these two environmental domains and deeper explore their relationship with access to healthcare.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by in France: The data were collected and stored in accordance with the reference methodology MR003 [Declaration No. 2205849 at the Commission for Data Protection and Liberties (CNIL)] each patient having been informed individually of the research under Article L1122–1 of the Public Health Code. In Germany: Ethikkommission der Universität zu Lübeck [AZ 18–172]. In Italy: Comitato Etico Lazio 1c/o A.O. San CamillobForlanini, Piazza Carlo Forlanini1, 00151 Roma [2143/CE Lazio 1]. In Portugal: Conselho de Ética e Deontologia, Universidade de Aveiro [CED-UA n.o 33/2018]. In Sweden: Regional Ethical Review Board in Göteborg, Sweden. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

JR: Writing – original draft. CP: Writing – review & editing. CA: Writing – review & editing, Supervision. NV: Supervision, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2024.1294999/full#supplementary-material

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Satisfaction with health care services in young people with cerebral palsy in the transition period: results from a European multicenter study

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Background: Young people with chronic health conditions and disabilities rely on the healthcare system to maintain their best possible health. The appropriate delivery and utilization of healthcare services are key to improve their autonomy, self-efficacy and employment outcomes. The research question of our study is directed toward investigating if poor availability and accessibility of healthcare services in general, as identified by unmet needs in healthcare, are associated with dissatisfaction with healthcare.

Methods: Within a European multicenter observational study, 357 young adults with cerebral palsy aged 19–28 were included. We assessed special healthcare needs, utilization of healthcare services, and satisfaction with healthcare applying the short-form of the YHC-SUN-SF, environmental and social variables (EAEQ) as well as indicators for severity of condition and functionality (e.g., GMFCS) of these participants based on a self-, assisted self- or proxy-reports. We used correlation analyses to explore associations between satisfaction with healthcare and respective indicators related to availability and accessibility of healthcare services as well as severity of the condition. In addition, we included reference values for satisfaction with heath care from young adults with various chronic conditions assessed within population-based surveys from some of the European countries included in the study.

Results: We identified several unmet healthcare needs, especially for widely used and established services (e.g., physical therapy). Satisfaction with healthcare (YHC-SUN-SF general and subscale scores) was moderate to high and almost consistently better for the sample of young adults with cerebral palsy as compared to reference values for young adults with various chronic conditions assessed within general population surveys). Correlation coefficients between

satisfaction with healthcare and utilization of services and (unmet) healthcare needs were low, also with different indicators for severity of the condition or functionality.

Conclusion: Young adults with cerebral palsy reports of unmet healthcare needs varied largely but showed substantial deficits in some aspects. This seems to have no impact on the satisfaction with healthcare those patients currently receive. We conclude that these are two different constructs and somewhat independent indicators to evaluate the quality of healthcare. Clinicians and other practitioners should consider this distinction when monitoring patient needs in their daily practice.

KEYWORDS

cerebral palsy, chronic condition, emerging adulthood, young adults, transition, special needs, healthcare utilization, satisfaction with care

Introduction

Over the last two decades, birth prevalence for cerebral palsy (CP) caused in the prenatal or perinatal period decreased substantially to 1.5 per 1000 live births in high income countries, i.e., Europe and Australia, while in regions of the global south it remained or increased to 3.4 per 1000 live births (1, 2). The reasons for the decline in more affluent regions are not fully understood, but better healthcare may play a role (3). Thus, access to healthcare services play an important role in preventing CP. However, the course of the condition and functional outcomes also depends on good quality healthcare. The impact of this lifelong condition often associated with severe disability makes CP a significant condition from a public health perspective (4). People with chronic health conditions and disabilities rely on the healthcare system to maintain their best possible health. Generally, they require interdisciplinary services within the healthcare system and multisectoral cooperation with social services, employment, housing, education and community resources for communication and mobility. Healthcare services can play an important part to improve, e.g., autonomy, self-efficacy, and employment outcomes (5).

The transitioning from pediatric care to adult medicine is associated with challenges for young people with special healthcare needs (6). This is accompanied by risks of a deterioration of care, the underutilization of services and ultimately poor health outcomes. Gaps in transitional care had been identified and recommendations for best practice were established (7, 8). Also, for young patients with widespread chronic diseases, care structures to address the obstacles associated with the transition process were established, e.g., transition programs (9). Such programs have also been introduced for young people with CP (10), but their availability and accessibility is far from being comprehensive, so does the fulfillment of the care needs of these patients, which are diversified and special (11, 12). The transition process must be individualized to the developmental needs of the adolescent/young adult and gradually work toward more autonomy. A recent qualitative study reported that the transition to adulthood for young adults with CP was far from gradual and was perceived as being "thrust into adulthood" (13).

Our research question is directed toward investigating if poor availability and accessibility of healthcare services are associated with dissatisfaction with healthcare. Given that limited access is known to be associated with impaired healthcare satisfaction, we assume that poor access to healthcare services, identified by unmet needs in healthcare, is associated with dissatisfaction with healthcare. To account for the patient's perspective, we use satisfaction with healthcare as a surrogate marker for good and adequate healthcare provision, given that patient-reported experience measures have been widely established in interdisciplinary healthcare and implementation studies.

Materials and methods

Design and samples

Cerebral palsy sample (CP)

We used data from SPARCLE3, a multicenter European observational population-based study combining the follow-up of the SPARCLE cohort to young adulthood (19–28 years) and a cross-sectional part allowing the recruitment of a larger sample of young people with CP. SPARCLE3 was implemented in five of the nine European regions originally investigated: South West and South East France (Haute-Garonne and Isère counties, respectively), North West Germany, Western Sweden (region of Goteborg), Central Italy (Viterbo area). The region of Porto (Portugal)

Abbreviations: BFMF, bimanual fine motor function; CP, cerebral palsy; EDACS, eating and drinking ability classification system; EAEQ, European Adolescent Environment Questionnaire; ECEQ, European Child Environment Questionnaire; FCCS, functional communication classification system; GMFCS, gross motor function classification system; HRQoL, health-related quality of life; MS, mean score; QoL, quality of life; SCPE, surveillance of cerebral palsy in Europe; SD, standard deviation; SPARCLE, study of PARticipation of children with cerebral palsy living in Europe; WHO, World Health Organization; YHC-SUN-SF, Youth Health Care - Satisfaction, Utilization and Needs - Short Form.

participated in the cross-sectional part. Further information is provided in the study protocol (14). The SPARCLE3 sample included young adults born between 31/07/1991 and 01/04/1997 with confirmed diagnosis of CP as defined by the SCPE (15). Out of 357 participants, 110 came from Germany, 105 from Portugal, 88 from France, 30 from Sweden, and 24 from Italy.

General population sample (GP)

Both in France and Germany, a population-based comparison group of young adults of the same age group was recruited with young adults participating in an online survey. Participants of the survey received incentives by a panelist who recruited males and females (in 50%/50% ratio) aged 19–29 years living in one of both participating countries (N = 4.051; France: n = 2080; Germany: n = 1964). In addition, comparison data from the other countries were available as well, but not on a population-wide level (Sweden: n = 987; Portugal: n = 105; Italy: n = 24).

Instruments

Youth Health Care - Satisfaction, Utilization & Needs - Short-Form measure (YHC-SUN-SF)

Specifically developed for adolescent self-report (age 15–25) on their satisfaction with their care provision (16), the YHC-SUN was derived from the CHC-SUN, reported by parents (17). This version was shortened to 30 items in SPARCLE3. The first module "*Receipt of services*" comprises 7 items plus the list of unmet needs (16 items) and the second module "*Satisfaction with care*" comprises 7 items (18). Answering options included: (a) services both needed and fully or partly used, (b) services not needed and not used, and (c) services needed but not used. We labeled the latter category as "unmet need" from the perspective of the user. Written in German, this questionnaire had no official translation available. The SPARCLE3 version has been translated with forward-backward procedure from German to English (in Lübeck) and afterwards by every country on their own in their language. Three following subscale-scores were calculated: "diagnosis/information," "doctors' behavior," and "patient centered care." The domains represented by these subscales were originally chosen for the short-form measure derived from the model of the original long-form measure, because all relate to the interaction between physician and patient. Item content covers satisfaction with information given about the condition and treatment choices, about the way doctors listened and explained as well about time spent and efforts made for the consultation. The YHC-SUN-SF measure was applied in both samples (CP, GP), except for the GP subsample from France.

European Adolescent Environment Questionnaire (EAEQ)

This instrument was developed in the SPARCLE project as an adaptation of the ECEQ [European Child Environment Questionnaire, (19)]. Lindsay Pennington (Newcastle) and Joaquim Alvarelhao (Porto) developed a new version specific for adulthood, comprising 61 items related to the physical, social and attitudinal environments. The questionnaire is divided into 8 parts: Physical environment at home (6 items), Physical environment at work/university/in day placement (5 items), Physical environment in public places (6 items), Access to transport (7 items), Access to health services and carer (9 items), Financial support (5 items), Attitude and support (20 items), Access to information (4 items). For this paper we used items from the Dimension "Access to health services and carer." The question "Do you need. . .?" offers the answer categories "no" and "yes," if yes a question follows whether the service is available or not. The EAEQ was assessed in the CP sample only.

Severity assessment

We also collected data on gross motor function (GMFCS) (20–22), hand function [Bimanual Fine Motor Function (BFMF)] (23), communication [Functional Communication Classification System (FCCS)] (24), and feeding (Eating and Drinking Ability Classification System (EDACS) (25), and vision and hearing impairments. Cognitive level was estimated by combining: information from the CP register at age five or later years, neuropsychological assessment if available, current school performance, and ability to self-report. Seizure frequency in the last year and the use of anticonvulsants were recorded. Severity assessments were applied in the CP sample only.

General health

The standard question "How is your health in general? Would you say it is . . ." was used in the European Social Survey (ESS) from round 1 (2002) to round 9 (2018). Respondents were asked to rate their current health on a five-step ladder ranging from very bad (1) to very good (5). Translations exist for SPARCLE countries (France, Germany, Italy, Portugal, Sweden). In 2016, 66.7% of the EU-28 population aged 18 and over reported that their health status was good or very good. At the other end of the spectrum, almost 1 in 10 (9.1%) persons perceived their health status to be bad or very bad (26). General health was assessed in both samples (CP, GP).

Data analysis

Descriptive statistics were used to describe the respondents' socio-demographic as well as clinical characteristics. Statistical tests (ANOVA/χ^2-test) as well as corresponding effect size measures and p-values were calculated to provide indicators of group differences. Spearman correlation analysis was used to investigate statistical associations between YHC-SUN-SF scores for satisfaction with care and different indicators for severity of condition and functioning. All quantitative statistical analyses were conducted using IBM SPSS Statistics 28.0.

Results

Sample

Among the 357 participants from the CP sample, 157 were female (44%), 216 lived with parents (60.5%), about 10% in facilities and 18% independently (**Table 1A**). A total of 117 responded by proxy-report by a carer (32.8%), less than a fifth had achieved more than secondary education. A total of 319 (89.4%) had a general practitioner and 236 (66.1%) a specialist for the condition. Young adults with CP had a mean age of 24.0 years (SD = 1.6 years) at the time of interview. Educational attainment

was much lower in the CP group. Noteworthy, self-rated health status (range 1–5) does not differ between the CP sample ($M = 2.08$, SD = 0.82) and the GP sample ($M = 2.08$, SD = 0.81; $p = 0.40$, $\eta = 0.01$).

Subtypes of CP represented in the sample were spastic unilateral (26.3%), spastic bilateral (54.9%), dyskinetic (10.5%) and ataxic (7.0%). Gross motor function (GMFCS) indicates that for nearly 40% of the participants with CP moving was either limited (18.2%) or even severely limited (20.2%), whereas more than one third is able to walk and climb stairs (35.3%). Around two third are able to communicate effectively in most situations on their own (58.8%) or with some help (7.6%), as indicated by the BFMFS. Further clinical characteristics may be found in Table 1B.

Unmet healthcare needs

We found a substantial number of unmet healthcare needs (Table 2): Subjectively reported unmet healthcare needs exceeded 10% (up to 17%) in most areas (12 out of 16, 75%), except for physical aids (5%) and communication aids (6%), home nursing (6%) as well as nutrition counseling (8%). Noteworthy, from those who reported not to get physiotherapy (33%, $n = 118$), almost a half stated they would need it (47%, $n = 55$); among those without support with filling applications (58%, $n = 208$), approximately a quarter would need it (28%, $n = 58$), a similar proportion appears (24%, $n = 61$) among those who reported not to get occupational therapy (69%; $n = 245$).

Special healthcare needs were assessed using two different assessments (YHC-SUN-SF, EAEQ). The overlap between corresponding responses of both measures is printed in bold in Table 3, ranging between 80 and 98% for physical therapy, occupational therapy and speech therapy. For the assessment of healthcare needs of other services, the terms used vary between both assessments and the range of corresponding responses is substantially impaired (self-help/support groups: 63–82%; social/counseling services: 43–70%) as compared to the aforementioned services.

Satisfaction with care

YHC-SUN-SF total and subscale (unweighted mean) scores as well as the single-item measure score (range 1–5) indicated moderate to high levels of satisfaction for the three different dimensions of healthcare with scores almost consistently higher on a significant level for the sample of young adults with CP as compared with data of young adults from the general population (Table 4).

Associations between satisfaction with care and unmet needs and severity of condition

Associations between satisfaction with care and the status of the chronic health condition in the CP sample: With a few exceptions, there were very low negative associations between healthcare satisfaction (YHC-SUN-SF) with different indicators of severity of the condition and functioning, respective correlations coefficients ranging from $r = -0.17$ to $r = 0.08$ (Table 5).

Moreover, except for provision of physical aids, rehabilitation measures, and nutritional/counseling therapy, low correlations coefficients were detected between satisfaction with care (YHC-SUN-SF) and utilization of healthcare services or healthcare needs for 3 of the 16 services assessed by the first module of the YHC-SUN-SF module (for a comprehensive list of these services see Table 3).

Discussion

Our study explored unmet needs in healthcare in young adults with CP and how these are associated with dissatisfaction with healthcare. We assumed that poor access to healthcare, identified by unmet needs in healthcare, is associated with dissatisfaction with healthcare.

We found a substantial number of *unmet healthcare needs*, especially for widely used and established services such as physical therapy and occupational therapy. One third of participants reported that they did not receive physical therapy; 17.3% stated that they did not perceive the need for such service and 15.4% reported unmet needs. Two thirds of the participants did not receive occupational therapy, 42% of respondents perceived no need for such services; however, the rate of unmet needs was high with 17.1%. This result confirms results provided by a recent study from Ireland (27). The authors report similar rates of unmet needs in physical therapy (23%) and occupational therapy (13%). A study with a convenience sample recruited online in France reported that finding an available physiotherapist was very difficult for 47% of the children compared to 58% of the adolescents and adults. Finding a physiotherapist trained in CP rehabilitation was reported as very difficult for 61% of children and adolescents and 66% of adults. Physiotherapy was provided in a private outpatient practice for 27% in adolescents, 41% in young adults and 57% in adults over 25 years. Regular communication between health professionals was less common in adults compared to adolescents, indicating a sharp decline in access to multiprofessional services. Generally, the access to and satisfaction with physical therapy in adults is much lower compared to young people with CP (28).

Occupational therapists can play a key-role in the transition process of young people with disabilities fostering self-determination but their services are often limited to school-based services or are discontinued at age 18 (29). A study with young people age 18–22 with CP in Ireland compared those who were discharged from pediatric services and those remaining. Especially the rate in occupational therapy dropped to 37.5% post discharge compared to 80.0% pre-discharge (30).

In this study, 16.5% of participants reported to receive speech and language therapy, but 14.8% reported unmet needs. A study from France compared health service use in different age groups and found a frequency of speech and language therapy in 17% of the ambulatory 18–24 year old participants and only 6% in non-ambulatory participants (31).

In psychosocial services, we found high rates of unmet needs: support with filling applications (16.2%), social services (14.8%),

TABLE 1A Characteristics of both samples.

		Cerebral palsy (CP)		General population (GP)		ANOVA/χ^2-test
		N	%	*N*	%	
Country						$\chi^2(1,4) = 515.87$, $p < 0.001$
	France	88	24.6%	2080	40.8	
	Germany	110	30.8%	1964	38.5	
	Italy	24	6.7%	24	0.5	
	Portugal	105	29.4%	47	0.9	
	Sweden	30	8.4%	987	19.3	
Sex						$\chi^2(1,1) = 9.60, p < 0.002$
	Male	200	56.0%	2426	47.5%	
	Female	157	44.0%	2676	52.5%	
Age						$F_{(1,5457)} = 5.66, p < 0.02$, $\eta = 0.03$
	Mean (SD), years	*24.03*	*(2.01)*	*24.45*	*(3.29)*	
Living environment						$\chi^2(1,4) = 16.50, p = 0.002$
	A big city (population over 200,000)	96	26.9%	1629	31.9%	
	The suburbs or outskirts of a big city (population over 200,000)	30	8.4%	668	45.0%	
	A town or a small city (population between 3,000 and 200,000)	159	44.5%	2070	40.6%	
	A country village (population less than 3,000)	61	17.1%	621	12.2%	
	A farm or home in the country	9	2.5%	113	2.2%	
	(Missing)	2	0.6%	1	0%	
Education						$\chi^2(1,8) = 578.65$, $p = 0.001$
	Early childhood educational development	111	31.1%	91	1.8%	
	Primary education	33	9.2%	45	0.9%	
	Lower secondary education	65	18.2%	559	11.0%	
	Upper secondary education	83	23.2%	1448	28.4%	
	Post-secondary non-tertiary education	12	3.4%	745	14.6%	
	Short cycle tertiary education	11	3.1%	612	12.0%	
	Bachelor or equivalent level	21	5.9%	927	18.2%	
	Master or equivalent level	16	4.5%	611	12.0%	
	Doctoral or equivalent level	–	–	61	1.2%	
	(Missing)	5	1.4%	3	0.1%	
Years of education						$F_{(1,5405)} = 26.06$, $p = 0.001$, $\eta = 0.07$
	Mean (SD)	*11.75*	*(4.95)*	*13.14*	*4.93*	
Type of report						*(n.a.)*
	Self-report without assistance	134	37.5%	5102	100%	
	Self-report with assistance	105	29.4%	–	–	
	Proxy-report	117	32.8%	–	–	
	(Missing)	1	0.3%	–	–	
General health						
	Mean (SD)	*2.08*	*(0.82)*	*2.04*	*0.81*	$F_{(1,5456)} = 0.71, p = 0.40$, $\eta = 0.01$
	Very good	84	23.5%	1267	24.8%	$\chi^2(1,4) = 1.66, p = 0.80$
	Good	181	50.7%	2618	51.3	
	Fair	75	21.0%	978	19.2%	
	Bad	14	3.9%	214	4.2%	
	Very bad	3	0.8%	24	0.5%	
	(Missing)	–	–	1	0%	

TABLE 1B Clinical and functional characteristics of sample with young adults with cerebral palsy (CP sample, n = 357).

Type of CP		N	%
	Spastic unilateral	94	26.3%
	Spastic bilateral	196	54.9%
	Dyskinetic	35	9.8%
	Dyskinetic chorea-athetotic	6	1.7%
	Ataxic	25	7.0%
	(Missing)	1	0.3%
GMFCS	*Mean (SD)*	*2.74*	*1.58*
I	Child walks and climbs stairs	126	35.3%
II	Child walks inside	50	14.0%
III	Child walks with limitations	44	12.3%
IV	Moving about is limited	65	18.2%
V	Moving about is severely limited	72	20.2%
BFMF	*Mean (SD)*	*2.58*	*1.43*
I	Without limitation	114	31.9%
II	Both hands limited in fine skills	80	22.4%
III	Child needs help with tasks	55	15.4%
IV	Child needs help and adapted equipment	59	16.5%
V	Child needs total human assistance	49	13.7%
FCCS	*Mean (SD)*	*2.12*	*1.50*
I	Effective communicator in most situations	210	58.8%
II	Effective communicator in most situations, but does need some help	27	7.6%
III	Effective communicator in some situations, small range of messages/topics to most familiar people	26	7.3%
IV	Assistance required in most situations, especially with unfamiliar people and communicates daily/routine needs and wants	56	15.7%
V	Communicates unintentionally with others, using movements and behavior	38	10.6%
EDACS	*Mean (SD)*	*1.84*	*1.24*
I	Safely and efficiently	215	60.2%
II	Safely but with some limitations to efficiency	51	14.3%
III	With some limitations to safety, maybe limitations to efficiency	45	12.6%
IV	With significant limitations to safety	24	6.7%
V	Unable to eat or drink safely/tube feeding	22	6.2%

CP, cerebral palsy; GMFCS, gross motor function classification system; BFMF, bimanual fine motor function; FCCS, functional communication classification system; EDACS, eating and drinking ability classification system; SD, standard deviation.

information (16.3%), and counseling about sexuality (11.3%). In our study 19.2% received psychotherapy but 16.3% reported unmet needs in this area. Given the high prevalence of mental health problems in young people with CP the provision of services appears to be poor (32, 33). In sexual counseling we would like to address the issue, that participants may not be aware of such service or sexuality may be considered a private issue not relevant to medical care. A Dutch study with young adults with CP described high levels of sexual problems mostly related to the fact of having CP and many young people wanted more information; however, in 90% the issue had never been discussed during rehabilitation treatment (34).

Unmet needs in rehabilitation (16.5%) and access to self-help groups (15.2%) indicate barriers to services aiming at fostering independence and self-efficacy. The need for home nursing was comparatively low in our sample. A study with a sample with CP aged 4–27 years demonstrated a considerable decrease of specialized rehabilitation services in the young adults compared to children and low levels of formal respite services and support groups/youth clubs (35).

The often abrupt transition from mostly well-equipped centers for integrated multiprofessional healthcare available for children and adolescents to a much more fragmented care in adulthood appears counter-intuitive as health in people with CP decreases over time and more but not less healthcare is required to prevent especially chronic pain, fatigue and declining walking ability (36). A systematic review of observational studies showed transition-associated poor outcomes including housing instability,

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TABLE 2 Healthcare needs as assessed with the YHC-SUN-SF (CP sample, *n* = 357).

Do you get...	Missing		Yes		Yes, partly		No and no need		No, but need		No receipt (total)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
Physiotherapy	0	*0.0*	211	*58.9*	29	*8.1*	62	*17.3*	55	*15.4*	117	*33.0*
Physical aids	1	*0.3*	172	*48.2*	54	*15.1*	113	*31.7*	17	*4.8*	130	*36.4*
Support with filling applications	1	*0.3*	116	*32.5*	32	*9.0*	150	*42.0*	58	*16.2*	208	*58.3*
Occupational therapy	1	*0.3*	83	*23.2*	28	*7.8*	184	*51.5*	61	*17.1*	245	*68.6*
Social services	0	*0.0*	77	*21.5*	31	*8.7*	196	*54.7*	53	*14.8*	249	*69.6*
Health services at work or school	5	*1.4*	63	*17.8*	25	*7.1*	228	*64.6*	36	*10.2*	264	*74.8*
Psychotherapy	2	*0.6*	68	*19.1*	16	*4.5*	213	*59.8*	58	*16.3*	271	*76.1*
Nutrition counseling	1	*0.3*	63	*17.6*	9	*2.5*	256	*71.7*	28	*7.8*	284	*79.6*
Speech therapy	0	*0.0*	47	*13.1*	12	*3.4*	245	*68.4*	53	*14.8*	298	*83.2*
Information	2	*0.6*	32	*9.0*	23	*6.5*	242	*68.0*	58	*16.3*	300	*84.3*
Communication aids	2	*0.6*	36	*10.1*	19	*5.3*	279	*78.2*	22	*6.2*	301	*84.3*
Home nursing	1	*0.3*	41	*11.5*	11	*3.1*	283	*79.3*	21	*5.9*	304	*85.2*
Rehabilitation	1	*0.3*	58	*16.2*	14	*3.9*	255	*71.4*	59	*16.5*	314	*88.0*
Self-help group	2	*0.6*	19	*5.3*	9	*2.5*	273	*76.7*	54	*15.2*	327	*91.9*
Telephone advice by medical professional	0	*0.0*	27	*7.5*	18	*5.0*	292	*81.6*	40	*11.2*	332	*92.7*
Counseling about sexuality	3	*0.8*	7	*2.0*	15	*4.2*	292	*82.3*	40	*11.3*	332	*93.5*

TABLE 3 Overlap of corresponding responses to YHC-SUN-SF and EAEQ items (CP sample, *n* = 357).

YHC-SUN-SF question: "Do you get..."*		EAEQ question: "Do you need..."*					
		...Physiotherapy?					
	Total**	No		Yes, I have it		Yes, but I don't have it	
	N	*n*	*%*	*n*	*%*	*n*	*%*
Yes, fully or partly	240	2	*0.8*	**228**	***95.0***	10	*4.2*
No, not needed	62	**58**	***93.5***	2	*3.2*	2	*3.2*
No, but I need it	54	4	*7.4*	4	*7.4*	**46**	***85.2***
(Missing)***	1						
		...Occupational therapy?					
		No		Yes, I have it		Yes, but I don't have it	
		n	*%*	*n*	*%*	*n*	*%*
Yes, fully or partly	110	11	*10.0*	**95**	***86.4***	4	*3.6*
No, not needed	184	**172**	***93.5***	5	*2.7*	7	*3.8*
No, but I need it	60	9	*15.0*	1	*1.7*	**50**	***83.3***
(Missing)	3						
		...Speech therapy?					
		No		Yes, I have it		Yes, but I don't have it	
		n	*%*	*n*	*%*	*n*	*%*
Yes, fully or partly	59	6	*10.2*	**47**	***79.7***	6	*10.2*
No, not needed	245	**239**	***97.6***	0	*0.0*	6	*2.4*
No, but I need it	52	8	*15.4*	0	*0.0*	**44**	***84.6***
(Missing)	1						
Do you have access to self-help groups?		Do you need support groups in your area?					
		No		Yes, I have it		Yes, but I don't have it	
		n	*%*	*n*	*%*	*n*	*%*
Yes, fully or partly	28	5	*17.9*	**20**	***71.4***	3	*10.7*
No, not needed	271	**223**	***82.3***	20	*7.4*	28	*10.3*
No, but I need it	54	16	*29.6*	4	*7.4*	**34**	***63.0***
(Missing)	4						
Do get advice from social services?		Do you need counseling services?					
		No		Yes, I have it		Yes, but I don't have it	
		n	*%*	*n*	*%*	*n*	*%*
Yes, partly	107	44	*41.1*	**46**	***43.0***	16	*15.0*
No, not needed	196	**138**	***70.4***	39	*19.9*	19	*9.7*
No, but I need it	53	16	*30.2*	10	*18.9*	**27**	***50.9***
(Missing)	1						

*Corresponding assessments of both questions are printed in bold. **Percentages are calculated based on row-wise frequency of cases. ***Number of missing values varies for each pair of variables (YHC-SUN-SF, EAEQ). EAEQ, European Adolescent Environment Questionnaire; YHC-SUN-SF, Youth Health Care - Satisfaction, Utilization and Needs - Short Form.

unemployment, difficulty forming relationships, increased hospital admission rates, and decreased use of rehabilitation services. Factors associated with improved outcomes included family participation, promotion of self-efficacy, and meeting the adult team before transition (7).

Moreover, as special healthcare needs were assessed using two different assessments in our study (YHC-SUN-SF, EACD) the overlap between corresponding responses to both different measures ranging between 80 and 98% for physical therapy and occupational therapy, providing even stronger evidence for the reliability of this finding.

Satisfaction with healthcare was moderate to good and almost consistently higher for the sample of young adults with CP as compared with data of young adults sampled from the general

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TABLE 4 Satisfaction with care (YHC-SUN-SF) for young adults with cerebral palsy from the SPARCLE study (n = 357) and young adults with different types of chronic health conditions from the general population in different European countries (GP sample, n = 14–703).

YHC-SUN-SF scores			Subscale "Information/ Diagnosis"	Subscale "Behavior of the doctor"	Subscale "Patient centered care"	Short-Form Global Score	Satisfaction with healthcare (single item)
		N	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)
Cerebral palsy	France	88	3.22 (0.93)	3.69 (1.00)	3.57 (1.07)	3.45 (0.85)	3.35 (0.91)
	Germany	110	2.90 (1.01)	3.65 (1.05)	3.46 (1.01)	3.32 (0.87)	3.35 (1.02)
	Italy	24	3.00 (0.96)	3.52 (1.13)	3.39 (1.14)	3.24 (0.97)	2.79 (0.93)
	Portugal	105	3.37 (0.96)	3.57 (0.97)	3.42 (1.02)	3.45 (0.87)	3.34 (0.99)
	Sweden	30	2.76 (1.08)	3.52 (1.07)	3.22 (1.11)	3.12 (0.99)	3.07 (1.02)
	Total (ANOVA)	*345*	$F_{(1,4)} = 4.21$, $p = 0.002$, $\eta = 0.05$	$F_{(1,4)} = 0.33$, $p = 0.86$, $\eta = 0.01$	$F_{(1,4)} = 0.65$, $p = 0.63$, $\eta = 0.01$	$F_{(1,4)} = 1.14$, $p = 0.0.35$, $\eta = 0.01$	$F_{(1,4)} = 2.16$, $p = 0.07$, $\eta = 0.02$
General population*	France**	–	–	–	–	–	–
	Germany	703	2.82 (1.03)	2.98 (1.08)	3.11 (1.03)	2.96 (0.92)	3.04 (1.06)
	Italy ***	–	–	–	–	–	–
	Portugal	14	2.61 (1.06)	3.43 (1.12)	3.68 (1.14)	3.24 (0.91)	3.14 (1.10)
	Sweden	217	2.37 (1.02)	2.70 (1.21)	2.88 (1.22)	2.64 (0.98)	2.57 (1.09)
	Total (ANOVA)	*935*	$F_{(1,3)} = 10.69$, $p = 0.000$, $\eta = 0.03$	$F_{(1,3)} = 4.57$, $p = 0.003$, $\eta = 0.02$	$F_{(1,3)} = 4.24$, $p = 0.005$, $\eta = 0.01$	$F_{(1,3)} = 7.22$, $p = 0.000$, $\eta = 0.02$	$F_{(1,3)} = 11.57$, $p = 0.000$, $\eta = 0.04$
ANOVA between both samples			$F_{(1,1272)} = 38.88$, $p = 0.00$, $\eta = 0.03$	$F_{(1,1279)} = 102.84$, $p = 0.00$, $\eta = 0.07$	$F_{(1,1276)} = 34.26$, $p = 0.00$, $\eta = 0.03$	$F_{(1,1279)} = 67.77$, $p = 0.00$, $\eta = 0.05$	$F_{(1,1290)} = 29.46$, $p = 0.00$, $\eta = 0.02$

*Subsamples of the general population surveys including a selection of young adults with chronic health conditions only. **The YHC-SUN-SF measure was not applied in the general population survey in France. ***Data from Italy are not reported, the subsample with a chronic condition is too small (n = 2). M, mean score; SD, standard deviation; YHC-SUN-SF, Youth Health Care - Satisfaction, Utilization and Needs - Short Form.

TABLE 5 Correlation coefficients for association between YHC-SUN-SF scores for satisfaction with care and different indicators for severity of condition and functioning (CP sample, n = 357).

Satisfaction with healthcare (YHC-SUN-SF)	*GMFCS*	*BFMF*	*EDACS*	*FCCS*	*Visual impairment*	*Hearing impairment*	*Seizures*	*Speaking Ability*
Global score	−0.126*	−0.148**	−0.112	−0.156*	−0.116	0.054	−0.009	−0.115*
"Information/ Diagnosis"	−0.147*	−0.173**	−0.112	−0.128*	−0.100	0.047	−0.022	−0.092
"Behavior of the doctor"	−0.082	−0.117*	−0.078	−0.112*	−0.086	0.039	0.004	−0.090
"Patient centered care"	−0.093	−0.103*	−0.097	−0.133*	−0.053	0.079	0.029	−0.101*

Spearman correlation coefficients.
*$p \leq 0.05$; **$p \leq 0.01$.

population. Likewise, in a recent study from our research group, we also found better quality of life for the environmental domain in young adults with CP as compared to reference values for young adults from a sample of the general population (37). The Transition Collaborative Group in UK used a different approach measuring satisfaction with healthcare: the Mind the Gap scale measures the difference or "gap" between a young person's ideal service and the service they have received. The results show decreasing levels of satisfaction with age; appropriate parental involvement was significantly associated with higher satisfaction in all age groups (38).

In this study, satisfaction with healthcare services was similar to that of the general population sample of the same age. Several factors may play a role: the recruitment in the general population survey did not exclude any other chronic health conditions. We also speculate that young adults with less exposure and interaction with healthcare providers may be more critical while the young adults with CP are likely to experience long lasting positive relations with at least some professionals in their healthcare. Higher involvement may lead to a higher appreciation of the services received.

Associations of healthcare satisfaction with severity of the condition and functional abilities were not substantial. A large French study including 354 children, 145 adolescents and 511 adults with CP measured satisfaction with motor rehabilitation services identified significant factors that decreased satisfaction: being an adolescent, higher levels of motor impairment, frequent pain, receiving physical therapy in private practice and poor access to a physiotherapist with specific CP training (39). Because the outcome was limited to satisfaction with a specific service whereas our study probed for satisfaction with healthcare in general the different findings are difficult to interpret.

Also, satisfaction with healthcare was not associated with utilization of healthcare services or (unmet) healthcare needs. Thus, unmet needs and satisfaction with healthcare seem to be unrelated constructs. In the Dutch PERRIN-PiP study a similar lack of association between satisfaction with another outcome was noted: their study revealed a dissociation between participation accomplishment and satisfaction with participation among adolescents with CP. The authors recommend not only to focus on accomplishment but also, if not mainly, on satisfaction (40).

Strengths and limitations

Our study reveals some *strong features*: We assessed a large sample of young adults with CP from different regional contexts and countries of Europe. In addition, a large proportion of this sample included patients that were longitudinally assessed throughout their childhood and adolescence (41–43). Moreover, we managed to collect reference data from young adults with various chronic health conditions, based on population-wide surveys in the respective countries. Finally, most of the constructs used in our analyses were assessed using different indicators, e.g., for (unmet) special healthcare needs (YHC-SUN-SF, EAEQ), for satisfaction with care (YHC-SUN-SF generic single item vs. total scale score) or severity of condition (e.g., GMFCS, BFMF).

One *limitation* of the study is that all results are based on self- or proxy-reported data only, thus we did not include any objective assessment for utilization of healthcare services. Thus, the validity of the subjective responses about individual behavior remains questionable. Furthermore, reference values were not eligible for all countries included and for some we collected only small samples. However, also the results from the countries with smaller sample sizes confirm the evidence provided by population-based surveys, indicating quite similar findings. Beside of this, we also missed to include CP and GP samples from Eastern European countries, thus our study is biased to Western Europe.

Conclusion

Young adults with CP reports of unmet healthcare needs varied largely but showed substantial deficits in some aspects. During the transition period there must be sustained support and access to condition specific treatments such as physical therapy, occupational and speech and language therapy, psychosocial services and counseling and care coordination to allow growth of self-determination and autonomy.

Unmet needs do not have an impact on the satisfaction with healthcare these patients currently receive and we conclude that these are two different concepts and separate indicators to evaluate the quality of healthcare services delivery.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

Ethics statement

The studies involving humans were approved by Germany: Ethikkommission der Universität zu Lübeck (AZ 18-172). Italy: 352 Comitato Etico Lazio 1c/o A.O. San Camillo Forlanini (2143/CE Lazio 1). Sweden: Regional Ethical 353 Review Board in Göteborg. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

HoM: Methodology, Writing – original draft. JA: Conceptualization, Investigation, Methodology, Writing – review and editing. CA: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Writing – review and editing. CC: Data curation, Investigation, Writing – review and editing. JF: Conceptualization, Investigation, Methodology, Project administration, Writing – review and editing. KH: Conceptualization, Investigation, Methodology, Writing – review and editing. MM: Conceptualization, Investigation, Methodology, Writing – review and editing. HeM: Conceptualization, Data curation, Investigation, Methodology, – review and editing. MR: Conceptualization, Investigation, Methodology, Writing – review and editing. SS: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Writing – review and editing. UT: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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ORIGINAL RESEARCH

Assessing the Adequacy of the Physical, Social, and Attitudinal Environment to the Specific Needs of Young Adults With Cerebral Palsy: The European Adult Environment Questionnaire

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Abstract

Objectives: To present the development of the European Adult Environment Questionnaire (EAEQ), to assess to what extent it covers the International Classification of Functioning, Disability and Health (ICF), and to describe the adequacy of the physical, social, and attitudinal environment to the specific needs of young adults with cerebral palsy (CP).

Design: Cross-sectional.

Setting: Administrative regions in France, Germany, Italy, Portugal, and Sweden.

Participants: Young adults with CP (N=357), with varying severity profiles, aged 19-28 years at time of interview (2018-20).

Interventions: Not applicable.

Main Outcome Measure(s): Physical, social, and attitudinal environment unmet needs.

Results: Relevant environmental factors (EFs) for young adults with CP were identified during focus groups in England and Portugal. EFs were mapped to the ICF environmental classification and the EAEQ analytical structure resulted from this linking procedure. It comprised 61 items, linked to 31 ICF environmental classification categories, and covered 4 of its 5 chapters. Content validity assessed with the bandwidth index (percentage coverage of ICF Core Sets for adults with CP) was satisfactory (79.3%). A descriptive analysis was carried out. Participants had a mean age of 24 years, 56% were men, 38% had severely limited mobility. Less than 16% reported unmet needs for EFs relating to home, college/work/day placement, and communication in the Products and technology chapter. Unmet needs were higher (>20%) for the other items in the Public use and Land development categories. Social support, attitudes, and understanding of relatives were often adequate to the participants' needs. The proportion of unmet needs varied by sex (women were more often concerned) and raised with increasing gross motor impairment.

Conclusion: The EAEQ describes in detail the adequacy of the environment to the specific needs of young adults with CP. Its ICF-based structure opens up possibilities for use in a universal conceptual framework.

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The publication of the International Classification of Functioning, Disability and Health (ICF)[1] in 2001 by the World Health Organization has markedly modified the definition of disability, integrating the environment as an integral part of the conceptual model of health. Disability now refers to the negative aspects of the interaction between individuals with health problems, their personal factors, and the environment. The environment is made up of environmental factors (EFs), which "make up the physical, social, and attitudinal environment in which people live and conduct their lives" and are identified as having an influence, positive or negative, on daily lives.[2] Despite this recognition, scientific research has mainly focused on the study of participation,[3] and the identification of its environmental barriers or facilitators.[4,5] Evidence is still lacking on how to achieve a comprehensive measure of the environment as a stand-alone concept.

Several methods have been used to characterize the environment.[6] In clinical studies, the focus was made on targeted and independent components, to assess the effect of environmental interventions on daily life.[6] Multi-item questionnaires, which study either specific (physical environment, mobility, etc)[7-10] or multiple components of the environment, are favored in observational studies. Many of these studies assess the interaction between the environment and activities of daily living, participation in the society or quality of life, to determine the extent to which the environment acts as an obstacle or a facilitator.[11-18] Some questionnaires contain objective measures about the presence or absence of certain EFs.[19-21] In contrast, subjective description of the environment is achieved by asking individuals about their need for EFs in addition to information about their availability.[12]

Environmental questionnaires can also be generic[17] or conversely, specific to a population. Although the ICF claims to be universally applicable, the environmental needs of people with disabilities are far from those of the general population. A number of disability-specific and/or age-specific ICF core sets have therefore been developed in recent years, to target relevant ICF domains specific to these population.[22] In 2022, Noten et al[23] proposed a specific ICF Core Set for adults with cerebral palsy (CP), as their environmental needs highly depend on the severity of their impairments and co-morbidities, as well as their personal aspirations.

Since 2003, and through 3 follow-up waves, the "Study of PARticipation of children with Cerebral palsy Living in Europe" (SPARCLE) research program has aimed to explore the effect of the environment on participation and quality of life of children (SPARCLE1),[24] adolescents (SPARCLE2),[25] and young adults (SPARCLE3)[26] with CP living in Europe. An integral part of the research was the development of a tool for measuring the adequacy of the proximal environment to the individual needs of the target population as a stand-alone concept and in its diversity. The European Child Environment Questionnaire (ECEQ) was developed in the first wave, and subsequently adapted for adolescents,[27-30] and finally for young adults with the development of the European Adult Environment Questionnaire (EAEQ). Our adaptations through the 3 waves aimed to maintain continuity in the way the environment was measured, and not necessarily in the content of the questions, adapted to each target age.

The aims of the present study were (a) to report on the development of the EAEQ, (b) to assess the extent to which this questionnaire covers the ICF environmental classification and more specifically the ICF Core Set for adults with CP, and report on the analytical structuration of the questionnaire, and (c) to describe the adequacy of the physical, social, and attitudinal environment to the specific needs of young adults with CP using data collected in SPARCLE3.

List of abbreviations:

CP	**cerebral palsy**
EAEQ	**European Adult Environment Questionnaire**
ECEQ	**European Child Environment Questionnaire**
EF	**environmental factor**
ICF	**International Classification of Functioning, Disability and Health**
SPARCLE	**Study of PARticipation of children with Cerebral palsy Living in Europe**

Methods

Development of the EAEQ

The concepts to be considered and the elements to be collected were identified on the basis of the ECEQ and on a literature review.[30] Semi-structured audio-recorded individual and group interviews were conducted with a convenience sample of young adults with CP, representing different levels of functioning and speech production, aged 19-30 years in the North of England (UK) (6 men, 6 women) and in Porto (Portugal) (5 men, 8 women). They were invited to participate through adverts distributed by college/rehabilitation staff and via newsletters of local support organizations. A face-to-face invitation was realized to provide to participants information about the study objectives and procedures (ie, to speak about the features of the environment in which they lived and studies/work that affected their daily lives, in order to develop a new tool to collect information in research). Face-to-face invitation and interviews were conducted by researchers who were experienced in qualitative studies among individuals with CP, and interviewing young people with communication difficulties and intellectual disabilities (LP (PhD) and Janice McLaughlin (PhD) at Newcastle University and a residential further education college (UK), and JA (PhD) and Diana Brandão (PhD) in Cerebral Palsy Rehabilitation Centre of Porto (Portugal)). They had no prior contact with the participants. During interviews, which lasted between 60 and 90 minutes, participant were asked to describe their home and who they lived with; their community; their studies or employment; their leisure activities; their methods of transport and the technology used to keep in touch with others and find information. We asked about who young people interacted with and what affected how frequently and easily they performed activities in the different environments. At each location, 1 researcher led the interviews, the second took field notes. Personal assistants accompanied the young adults. After transcribing the interviews, content analysis and coding were carried out by 2 researchers independently. The researchers then met online to consider the coding across the 2 locations and agreed an initial set of items. Respondents' understanding of the items was assessed through cognitive interviews and focus groups. The questionnaire was structured by life domains to follow a logical flow during administration (supplemental table S1).

ICF-based linking procedure, analytical structure, and content examination

The content of the EAEQ was linked to the ICF environmental classification using the established ICF linking rules.[31,32] Two

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assessors (J.A., C.P.) independently identified the meaningful concept(s) per EAEQ item and matched each meaningful concept to the ICF environmental classification category that most accurately represented its content, using the second level of the hierarchy (eg, E115). When an item contained more than 1 meaningful concept, each of them was linked. In case of disagreement between assessors, consensus was reached by discussion. Meaningful concepts that could not be linked were marked as "not covered" by the ICF environmental classification.

The analytical structure of the questionnaire was based on this linkage phase, items grouped by ICF environmental classification category. We considered each category identified as a latent construct. Based on the decision rules proposed in the literature to help identify the measurement model underlying a latent construct,[33] we concluded that items grouped in same construct were not necessarily inter-correlated, but provided information in order to fully define the construct. Thus, formative measurement models were chosen for each EAEQ latent construct. Therefore, the validity analysis was restricted to content validity.

Content density and diversity ratios were calculated to describe the content in relation to the ICF environmental classification. Content density refers to the average number of concepts per item. The higher the value, the greater the number of meaningful concepts per on average. Content diversity ratio corresponds to the number of distinct ICF environmental classification categories in the questionnaire divided by the number of meaningful concepts. A value close to zero indicates that, on average, 1 ICF environmental classification category is covered by several meaningful. The bandwidth index was calculated to assess to what extent the EAEQ covers the ICF environmental classification.[34-36] We considered the 29 distinct categories of the ICF Core Set for adults with CP as denominator for the calculation.[23] Bandwidth corresponds to the percentage of coverage of these ICF Core Set categories by the EAEQ items. The greater the bandwidth, the greater the coverage of the ICF Core Set.

SPARCLE3: study design and population

SPARCLE3 is the third wave of the SPARCLE program. Detailed methods are described elsewhere.[26] In brief, the design combined a longitudinal follow-up of young people with CP who were previously sampled from population-based registries or from multiple sources in European administrative regions (Haute-Garonne and Isère counties in France, Viterbo region in Italy, Goteborg region in Sweden, and Lübeck region in Germany) and who had participated in at least 1 of the 2 first waves of the SPARCLE study, and an additional sample with the same eligibility criteria who had never participated in SPARCLE, recruited from multiple sources in Lübeck and Porto Metropolitan area (Portugal). Because of the exploratory nature of this study, no sample size calculations were made, as data access was dependent on the SPARCLE3 study design, the flowchart of which is shown in figure 1. Individuals with confirmed diagnosis of CP, that is, with an abnormal pattern of movement and posture (spastic, dyskinetic, or ataxic) caused by a non-progressive injury to the immature brain, that may be associated with epilepsy, difficulties of cognition, communication, feeding, vision and hearing, secondary musculoskeletal problems,[37] who were born between 07/31/1991 and 04/01/1997, and aged 22-27 years at the time of data collection (2018-2020) were eligible.

Data collection

The young adults completed standardized home interviews conducted by trained research associates, if necessary with assistance. If not possible, a relative or a personal assistant closely involved in the daily life was interviewed as a proxy.[38]

The following characteristics were collected: sex, age, region of residence, population size of place of residence, walking ability using the Gross Motor Function Classification System,[39] hearing and visual impairment using the Washington Group Short Set on Functioning,[40] speech and communication skills using the Viking

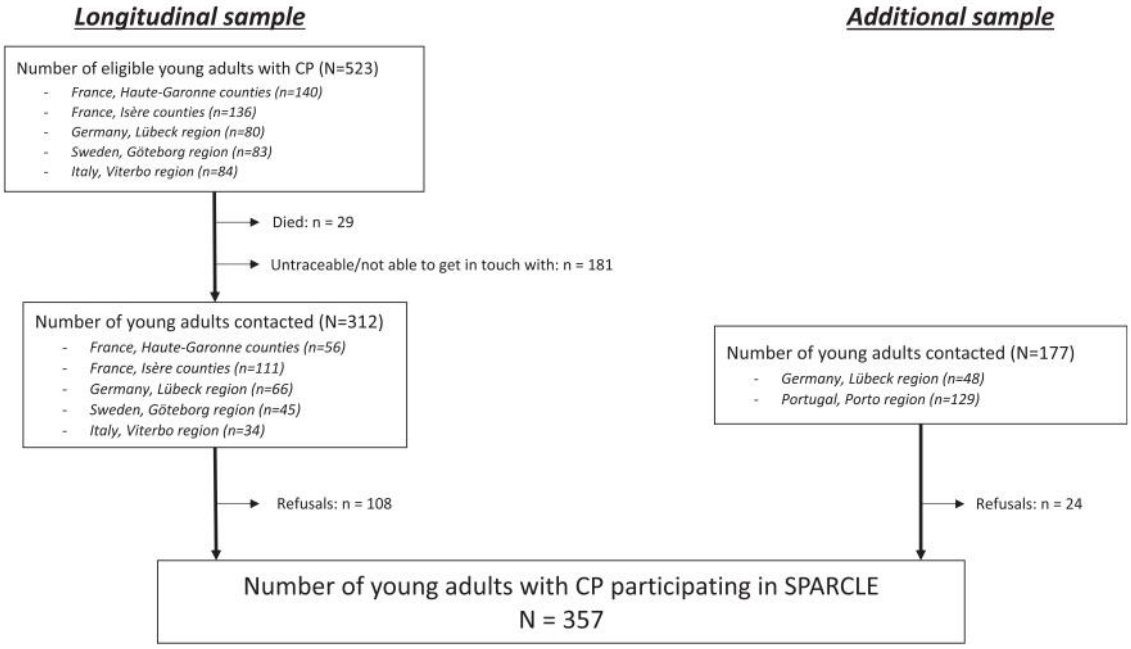

Fig 1 Flow chart of the study. Longitudinal and cross-sectional recruitment process of the 357 young adults of the CP sample of SPARCLE3.

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Speech Scale,[41] and the Functional Communication Classification System,[42] respectively. Those instruments are widely used in each country with semantic and conceptual equivalence. They were presented in details in supplemental table S2. The EAEQ contains 2 types of items collecting (1) the need for the EF (Needed/not needed) and, if needed, its availability (Available/not available), or (2) only availability, the need being considered a priori to be common to all individuals. The responses "Needed and not available" reflected an unmet environmental need, while the responses "Not needed" or "Needed and available" were considered to be an environment that meets the need.

Statistical analysis

Descriptive analyses were conducted. Despite some young people were interviewed outside the target age range, they have been retained in the analysis. Sociodemographic, impairments, and EAEQ data were summarized as counts and proportions. For construct of the EAEQ, median, minimum, and maximum percentage of unmet needs were estimated. For each item, proportions of unmet needs for the sample were presented as a whole, by sex, by walking ability, by region, and by population size of place of residence. As missing data were scarce (proportion ranged from 0% (18 items) to 4.0%), no specific statistical methods were used to handle them: the complete dataset was used for all analysis described above. Analyses were performed with STATA 14.2 (StataCorp, Texas, USA).

Results

Development of the EAEQ

Concepts identified as relevant during interviews are listed in table 1. The first version contained 119 items, of which 61 were retained after assessment of item comprehension.

Table 1 Environmental concepts identified as relevant by young adults with CP during focus groups in the developmental phase of the EAEQ

Family, service providers, and public:
- Understanding of needs and positive attitudes
- Communicating using language that is easy to understand
Availability of:
- Appropriate education and employment
- Assistive technology in education
Accessibility of the built environment including streets, buildings, and transport
Adaptation and availability of leisure facilities
Flexibility of personal assistance personnel and consistency and reliability of providers of support
Access to adequate health services
Financial support programs
Access to:
- Internet connection
- Social media

ICF-based linking procedure, analytical structure, and content examination

The 2 assessors identified 79 and 71 meaningful concepts, and linked 73 and 64 of these to the ICF environmental classification, respectively. Forty-four of these linking decisions were common. After consensus, 77 meaningful concepts were retained: 6 were considered "not covered" by the ICF environmental classification, the other 71 were linked to 31 distinct categories of the ICF environmental classification, covering all chapters except chapter 2 "Natural environment and human-made changes to environment". The EAEQ analytical structure is presented in table 2. Content density and content diversity ratios were 1.26 (77/61) and 0.40 (31/77), respectively. In total, 79.3% of the ICF Core Set for adults with CP was covered (bandwidth index: 23/29 × 100). Items containing only "not covered" meaningful concepts were classified in an additional category, named "Understand and be understood", which examines whether people in a person's environment understand their way of talking and using language.

Adequacy of the environment, SPARCLE3 study

The sample consisted of 357 young adults with CP, mean age 24 years (SD 2 years), 56% were men and 38.4% were unable to walk (table 3). Overall, 67.1% of participants completed the questionnaire themselves, with or without assistance.

The detailed responses to the EAEQ are described in supplemental table S3 according to ICF environmental classification chapters. Overall, the percentage of individuals reporting an unmet need varied between 0.6% and 53.1% (median: 16%) (fig 2). In the "Products and technology" chapter, the median percentage of participants reporting an unmet need was 12.1%. It varied from 4.2% (item "modified wheelchair") to 35.3% ("ramps in public places"). Unmet needs were more often observed for items of "Design, construction and building products and technology of buildings for public use/for culture, recreation and sport" and "Products and technology of land development" categories. In the "Support and relationships" chapter, unmet needs ranged from 0.6% to 10.2% (median: 5.2%), with higher proportions on items related to "distant" relations that is, strangers in public places, health care professionals, colleagues, and students. A similar pattern was found for the chapters "Attitudes" (median: 9.8%), and "Understand and be understood" (median: 13.5%), with as up to 35.7% of participants reporting a lack of understanding from the general public/strangers of their speech/way of talking. In the "Services, systems and policies" chapter, unmet needs ranged from 9.3% for the safety of the local area to 53.1% for the information about accessibility of places in the area.

Table 4 presents unmet needs according to sociodemographic characteristics and impairment profile. For almost 70% of items (42/61), the proportion of reported unmet needs was higher for women than for men (mean difference 4.9 points, whereas the mean difference for items where men reported unmet needs more frequently than women was 2 points). The "Communication services, systems and policies" category was the 1 with the largest sex differences, with more than 10-point difference for access to information about activities, accessibility of places in the area and employment/education. For 56 items, non-walkers had a higher proportion of unmet needs than walkers, with a particularly marked difference for the "Design, construction and building products and technology of buildings for public use/for culture, recreation and sport" category and the "Products and technology

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Table 2 Analytical structure of the EAEQ correspondent to ICF chapter and sub-domain headings, ICF reference codes, and number of elements per chapter and sub-domains

Headings of ICF Chapters and ICF Categories	ICF Code	Number of Items
Products and technology	**Chapter 1**	**19**
Design, construction, and building products and technology of buildings for private use	**E155**	**4**
1. Enlarged rooms or extensions	*E155*	
2. Adaptations to the entrance of your home	*E155*	
3. Adapted bathroom	*E155*	
4. Adaptations to other rooms (eg, work surfaces in kitchen)	*E155*	
Products and technology for personal use in daily living	**E115**	**1**
5. Aids/adapted equipment for personal care, cooking, housekeeping, and etc.	*E115*	
Products and technology for communication	**E125**	**2**
6. Communication aids at home	*E125*	
10. Communication aids at work/college/day placement	*E125*	
Products and technology for education and for employment	**E130/E135**	**1**
9. Adapted equipment (eg, computer)	*E130/E135*	
Products and technology for personal indoor and outdoor mobility and transportation	**E120**	**2**
18. Adapted vehicle for getting around	*E120*	
22. Modified wheelchair	*E120*	
Design, construction, and building products and technology of buildings for public use/for culture, recreation, and sport	**E150/E140**	**7**
7. Adaptations to make all areas at college/work accessible	*E150*	
8. Adapted toilets at work/college/day placement	*E150*	
12. Ramps in public places	*E150*	
13. Adapted toilets or toilet facilities	*E150*	
14. Lifts/escalators	*E150*	
15. Adapted doorways	*E150*	
17. Thinking about the things you like to do outside your home, eg, cinema, doing sport, watching sport, clubs, restaurants - Are the local leisure facilities accessible?	*E150/E140*	
Products and technology of land development	**E160**	**2**
16. Accessible pavements in your town or village center	*E160*	
57. Are public places accessible for you to move around?	*E160*	
Support and relationships	**Chapter 3**	**8**
Acquaintances, peers, colleagues, neighbors, and community members/Personal care providers and personal assistants/Health professionals	**E325/E340/E355**	**2**
11. Extra time to do what you need to do	*E325*	
39. Do people around you (personal assistant/students/colleagues/health care professionals) help you to do things at work/college/day placement?	*E325/E340/E355*	
Immediate family, extended family, friends	**E310/E315/E320**	**3**
23. Help from family and friends to get around	*E310/E315/E320*	
38. Do family and friends help you to do things at home?	*E310/E315/E320*	
44. Do you get emotional support from family and friends?	*E310/E315/E320*	
Personal care providers and personal assistants	**E340**	**2**
31. A personal assistant to help you at home	*E340*	
32. A personal assistant to help you at work/college/day placement	*E340*	
Strangers	**E345**	**1**
40. Do people in public places help you to do things?	*E345*	
Attitudes	**Chapter 4**	**6**
Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members/of health professionals	**E425/E450**	**3**
28. Teachers, therapists, and doctors who listen to your views	*E425/E450*	
42. Do students/colleagues/health care professionals have a positive attitude toward you?	*E425/E450*	
53. Do staff at college/placement/work understand your needs (medical condition)?	*E425*	
Individual attitudes of immediate family members/of extended family members/of friends	**E410/E415/E420**	**2**
41. Do family and friends have a positive attitude toward you?	*E410/E415/E420*	
45. Do your family and friends encourage you to do things and to try things out?	*E410/E415/E420*	

(*continued on next page*)

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Table 2 (*Continued*)

Headings of ICF Chapters and ICF Categories	ICF Code	Number of Items
Individual attitudes of strangers	**E445**	**1**
43. Do the general public/strangers have a positive attitude toward you?	*E445*	
Services, systems, and policies	**Chapter 5**	**22**
Social security services, systems, and policies	**E570**	**5**
33. Financial support/grants from the government/council for: Equipment such as wheelchairs, communication aids, hoists, bathing aids, etc.	*E570*	
34. Financial support/grants from the government/council for: Home modifications	*E570*	
35. Financial support/grants from the government/council for: A personal assistant	*E570*	
36. Financial support/grants from the government/council for: Travel/transport	*E570*	
37. Financial support/grants from the government/council for: Leisure activities/holidays	*E570*	
Associations and organizational services, systems, and policies	**E555**	**1**
29. Support groups in your area	*E555*	
General social support services, systems, and policies	**E575**	**1**
30. Counseling services	*E575*	
Health services, systems, and policies	**E580**	**4**
24. Specialized therapy services such as Physiotherapy	*E580*	
25. Specialized therapy services such as Speech therapy	*E580*	
26. Specialized therapy services such as Occupational therapy	*E580*	
27. Specialized therapy services such as A specialist doctor who knows about your condition	*E580*	
Communication services, systems, and policies	**E535**	**5**
46. Do you have access to social media? (eg, texting, FB, Twitter)	*E535*	
58. Is information about services easy to understand?	*E535*	
59. Is information about activities in your area, eg, cinema, easy to understand?	*E535*	
60. Is there information about accessibility of places in your area?	*E535*	
61. Is information about employment/education available to you?	*E535*	
Open space planning services, systems, and policies	**E520**	**1**
19. Accessible car parking in places where you need to park	*E520*	
Transportation services, systems, and policies	**E540**	**2**
20. Adequate public transport (buses/trains/taxis)	*E540*	
21. Accessible public transport (buses/trains/taxis)	*E540*	
Civil protection services, systems, and policies	**E545**	**2**
55. Is public transport safe?	*E545*	
56. Is your local area safe?	*E545*	
Education and training services, systems, and policies	**E585**	**1**
54. Does your college/employer/day placement provide for your needs?	*E585*	
Understand and be understood	**NC**	**6**
47. Do your family and friends understand your speech/way of talking?		
48. Do people around you (personal assistant/students/colleagues/health care professionals) understand your speech/way of talking?		
49. Do the public/strangers understand your speech/way of talking?		
50. Do your family and friends communicate in a way that is easy to understand?		
51. Do people around you (personal assistant/students/colleagues/health care professionals) communicate in a way that is easy to understand?		
52. Do the public/strangers communicate in a way that is easy to understand?		

Abbreviations: FB, Facebook; nc, not covered by ICF.

of land development" category (average difference 31.4 points and 32.7 points, respectively). Conversely, the difference between walkers and non-walkers in the "Attitudes" chapter was small for each item (average difference 3.8 points). We observed the greatest variability between participating countries for the "Public places accessible to move around" item, with French participants declaring 21.8% of unmet needs and Italian participants 62.5%. For more than 50% of the questionnaire items, the frequency of unmet needs was higher for participants living in medium-sized cities (3000 to 200,000 inhabitants) than in other locations.

Discussion

Like the ECEQ, the EAEQ was developed to measure the adequacy of the environment to the individual needs of people with CP. New items identified as relevant to the target age and condition were added in the adult version. The analysis showed a high coverage of the ICF environmental classification, resulting in satisfactory content validity. "Natural environment and human-made changes to environment" was the only chapter of the ICF environmental classification that does not appear in the EAEQ. This

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Table 3 Sociodemographic and impairment characteristics of young adults with CP participating in the SPARCLE3 study (N=357)

	n	%
Region		
South West and South East France	88	24.7
North West Germany	110	30.8
Central Italy	24	6.7
Central Portugal	105	29.4
Western Sweden	30	8.4
Sex		
Men	200	56.0
Women	157	44.0
CP subtypes		
Bilateral spastic	196	55.1
Unilateral spastic	94	26.4
Dyskinetic	41	11.5
Ataxic	25	7.0
Missing	*1*	
Population size of place of residence		
<3000 inhabitants	70	19.7
3000–200,000 inhabitants	159	44.8
>200,000 inhabitants	126	35.5
Missing	*2*	
Age (years)	*Mean*	*SD*
	24	2
	Min	*Max*
	19	28
Walking ability (GMFCS[39])		
Level I, II, III: walks, even with limitations	220	61.6
Level IV, V: unable to walk, wheelchair	137	38.4
Hearing impairment		
No	332	93.3
Yes	24	6.7
Missing	*1*	
Visual impairment		
No	243	68.0
Yes	114	32.0
Speaking ability (VSS[41])		
Not affected	189	52.9
Imprecise but usually understandable to unfamiliar listeners	52	14.6
Unclear and not usually understandable to unfamiliar listeners	39	10.9
No understandable speech	77	21.6
Communication ability (FCCS[42])		
Effective communicator in most situations	210	58.8
Effective communicator but does need some help	27	7.6
Effective communicator but small range of messages/topics to most familiar people	26	7.3
Assistance required in most situations	56	15.7
Communicates with others using undirected movement and behavior	38	10.6

Abbreviations: FCCS, Functional Communication Classification System[42]; GMFCS, Gross Motor Function Classification System[39]; SPARCLE3, Study of PARticipation of children with Cerebral palsy Living in Europe – third wave; VSS, Viking Speech Scale.[41]

chapter was also absent from the environmental ICF Core Set for adults with CP.[23] Some categories of the environmental ICF Core Set for adults with CP were also not covered by the EAEQ, partly because they are far removed from everyday concerns such as the attitudes of people in position of authority. Nevertheless, the EAEQ goes beyond the core set by including 8 additional ICF environmental classification categories, allowing a fine-grained description of the environment. If we consider the environment from the perspective of ecological theory,[43-45] the EFs identified in the EAEQ only represent aspects of the environment close to the individual. The ecological model suggests that a more distant environment might also influence lifestyle and activities, but corresponding features did not emerge during the focus groups.

The proportion of unmet needs varied between EAEQ items. Of all the services explored, those related to communication and information matched very poorly the needs. Provision of appropriate information and access to communication technologies have previously been reported to improve the lives of persons with disabilities and to support meaningful inclusion in society.[46,47] Products and technologies for personal indoor and outdoor mobility and transportation, as well as social support from close family and friends, are also vital areas that were identified as facilitating daily lives of individuals with disabilities.[48] They were frequently rated as a met need among SPARCLE3 participants. On the opposite, "Design, construction, and building products and technology of buildings for public use" were identified as significant environmental barriers in the same study[48] and were frequently reported as unmet in our study.

Study limitations

Although our choice was to characterize the environment as a stand-alone concept, we cannot rule out the fact that participants answered the questions thinking about the potential effect of EFs on participation. Nevertheless, our approach has made it possible to limit this effect, with questions formulated to explore the availability of EFs only. Secondly, we defined the environmental construct as formative models. As such, there was no construct validity hypothesis. Comparison of our questionnaire with other tools is limited to content validity, which was satisfactory for the EAEQ.

Because of the limited geographic coverage of the population-based registers on which recruitment was initially based, attrition during follow-up, and the specific additional recruitment in wave 3, the SPARCLE3 sample of young adults with CP is not representative. We have no data at this age to compare the profile of these young people in terms of disability or social characteristics. Nevertheless, we were able to recruit young people with a severe disability profile (38.4% with Gross Motor Function Classification System IV-V), who are very often excluded from the studies.

Implication for practice and research

This questionnaire makes it possible to collect the EFs that are useful to individuals with CP and to analyze whether their availability, modification, or adaptation could improve the achievement

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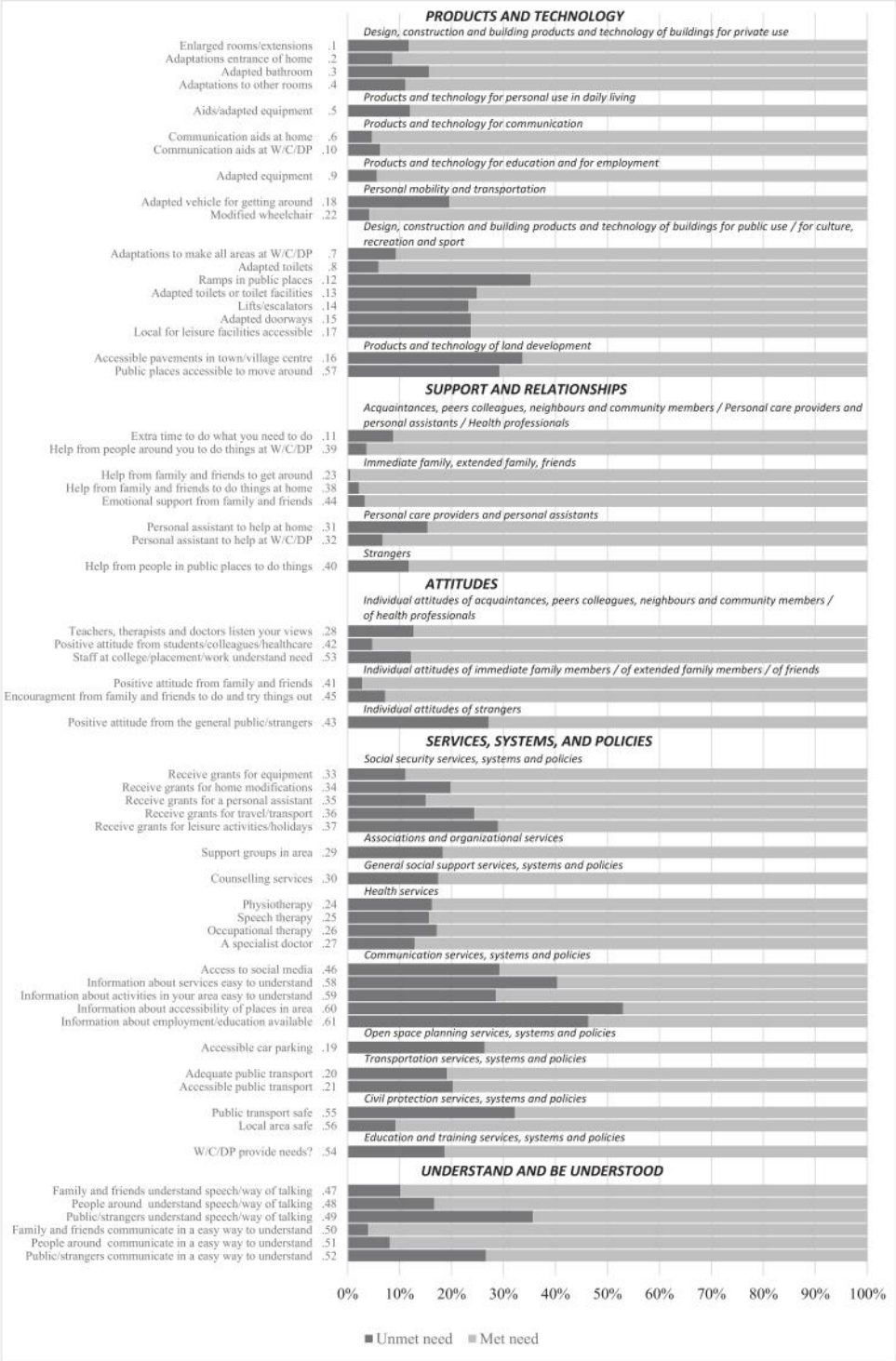

Fig 2 Percentage of unmet and met needs for each of the 61 questionnaire items, structured in its analytical form (ie, based on ICF environmental classification). All percentages are generated on the data available for each item.

of daily activities, participation, and quality of life. Despite the large set of items, which could make the questionnaire tedious to complete, we observed a high response rate on all items (over 96%), that highlight the acceptability of the EAEQ. This suggests the possibility of widespread use in clinical practice. By systematically measuring a wide range of EFs, health care professionals could gain a clear idea of the extent of their patients' needs and help them to make the necessary compensations. Analysis of geographic or temporal differences in the frequency of participation or level of quality of life, coupled with an overall view of unmet environmental needs, could provide the public authorities with the elements for a policy of accessibility and integration of people with disabilities into society. Finally, independent measurement of the environment opens new avenues for studying the associations between environment and a series of patient-reported outcomes.

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Table 4 Percentage of young adults with CP participating in the SPARCLE3 study with unmet needs for each EAEQ item, by sex, GMFCS level, region, and population size of place of residence (N=357)

	Unmet Need (%)		Unmet Need (%)		Unmet Need (%)					Unmet Need (%)		
	Sex		GMFCS Level		Region					Population Size of Place of Residence*		
Headings of ICF Chapters and ICF Categories	Male n=200	Female n=157	I, II, III n=220	IV, V n=137	Fr n=88	De n=110	It n=24	Pt n=105	Se n=30	<3000 inhabitants n=70	3000–200,000 inhabitants n=159	>200,000 inhabitants n=126
Products and technology												
Design, construction, and building products and technology of buildings for private use												
1. Enlarged rooms or extensions	9.5	14.6	4.5	23.4	10.2	10.9	12.5	14.3	10.0	4.3	13.8	13.5
2. Adaptations to the entrance of your home	7.0	10.8	4.5	15.3	8.0	6.4	8.3	13.3	3.3	2.9	10.7	9.5
3. Adapted bathroom	14.0	17.8	10.0	24.8	17.0	9.1	33.3	18.1	13.3	7.1	20.1	15.1
4. Adaptations to other rooms (eg, work surfaces in kitchen)	9.5	13.4	5.9	19.7	11.4	5.5	16.7	13.3	20.0	7.1	12.6	11.1
Products and technology for personal use in daily living												
5. Aids/adapted equipment for personal care, cooking, housekeeping, etc.	9.5	15.3	8.2	18.2	13.6	4.5	8.7	20.0	10.0	7.1	15.2	11.1
Products and technology for communication												
6. Communication aids at home	5.0	4.5	1.8	9.5	6.8	0.9	4.2	5.7	10.0	5.7	6.9	1.6
10. Communication aids at work/college/day placement	6.1	6.5	2.7	12.0	8.0	4.7	0.0	6.7	10.7	7.1	8.3	3.2
Products and technology for education and for employment												
9. Adapted equipment (eg, computer)	5.6	5.8	3.2	9.8	5.7	5.6	4.2	4.8	10.7	8.6	7.1	2.4
Products and technology for personal indoor and outdoor mobility and transportation												
18. Adapted vehicle for getting around	16.5	23.6	15.0	27.0	20.5	10.9	33.3	29.5	3.3	11.4	22.6	20.6
22. Modified wheelchair	4.0	4.5	3.6	5.1	2.3	1.8	4.2	9.5	0.0	0.0	6.9	3.2
Design, construction, and building products and technology of buildings for public use/ for culture, recreation, and sport												
7. Adaptations to make all areas at college/work accessible	9.6	9.0	7.8	12.0	8.0	8.4	20.8	8.6	10.7	11.4	12.8	4.0
8. Adapted toilets at work/college/day placement	7.1	4.5	2.3	12.0	4.5	1.9	16.7	7.6	10.7	5.7	9.6	1.6
12. Ramps in public places	31.3	40.4	15.0	68.7	31.8	34.3	37.5	33.7	53.3	32.9	37.6	33.3
13. Adapted toilets or toilet facilities	21.5	29.3	8.6	51.1	12.5	28.2	41.7	21.0	50.0	22.9	26.4	23.8
14. Lifts/escalators	20.5	26.8	8.2	47.4	18.2	30.9	33.3	21.0	10.0	27.1	18.9	26.2
15. Adapted doorways	21.5	26.8	8.2	48.9	25.0	25.5	20.8	20.0	30.0	24.3	21.4	26.2

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Table 4 (*Continued*)

Headings of ICF Chapters and ICF Categories	Unmet Need (%) Sex: Male n=200	Unmet Need (%) Sex: Female n=157	Unmet Need (%) GMFCS Level: I, II, III n=220	Unmet Need (%) GMFCS Level: IV, V n=137	Unmet Need (%) Region: Fr n=88	Unmet Need (%) Region: De n=110	Unmet Need (%) Region: It n=24	Unmet Need (%) Region: Pt n=105	Unmet Need (%) Region: Se n=30	Unmet Need (%) Population Size of Place of Residence*: <3000 inhabitants n=70	Unmet Need (%) Population Size of Place of Residence*: 3000–200,000 inhabitants n=159	Unmet Need (%) Population Size of Place of Residence*: >200,000 inhabitants n=126
17. Thinking about the things you like to do outside your home, eg, cinema, doing sport, watching sport, clubs, restaurants - Are the local leisure facilities accessible?	19.1	29.7	12.3	42.2	20.5	24.3	29.2	24.8	23.3	28.6	20.1	25.4
Products and technology of land development												
16. Accessible pavements in your town or village center	31.5	36.5	20.0	55.9	34.1	29.4	54.2	34.3	30.0	30.0	34.6	34.1
57. Are public places accessible for you to move around?	26.1	33.3	17.9	47.4	21.8	24.5	62.5	34.3	24.1	27.1	34.8	23.0
Support and relationships												
Acquaintances, peers colleagues, neighbors, and community members/Personal care providers and personal assistants/Health professionals												
11. Extra time to do what you need to do	9.6	7.7	10.0	6.8	12.5	8.4	4.2	6.7	10.7	10.0	7.1	10.3
39. Do people around you (personal assistant/ students/colleagues/health care professionals) help you to do things at work/college/ placement?	3.5	3.8	4.1	3.0	4.5	4.6	4.2	2.9	0.0	5.7	5.1	0.8
Immediate family, extended family, friends												
23. Help from family and friends to get around	1.0	0.0	0.5	0.7	0.0	0.0	0.0	1.0	3.3	0.0	1.3	0.0
38. Do family and friends help you to do things at home?	2.0	2.6	0.9	4.4	3.4	0.0	0.0	2.9	6.7	2.9	2.5	1.6
44. Do you get emotional support from family and friends?	3.5	3.2	4.1	2.2	0.0	2.8	8.3	5.7	3.3	0.0	4.4	4.0
Personal care providers and personal assistants												
31. A personal assistant to help you at home	14.0	17.2	7.7	27.7	9.1	19.1	4.2	23.8	0.0	14.3	18.9	11.9
32. A personal assistant to help you at work/ college/day placement	6.1	7.7	5.0	9.6	4.6	9.3	8.7	7.6	0.0	10.0	7.7	4.0
Strangers												
40. Do people in public places help you to do things?	13.5	9.6	5.9	21.2	13.6	12.7	20.8	8.6	6.7	17.1	10.7	10.3

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Headings of ICF Chapters and ICF Categories	Unmet Need (%) Sex: Male n=200	Unmet Need (%) Sex: Female n=157	Unmet Need (%) GMFCS Level: I, II, III n=220	Unmet Need (%) GMFCS Level: IV, V n=137	Unmet Need (%) Region: Fr n=88	Unmet Need (%) Region: De n=110	Unmet Need (%) Region: It n=24	Unmet Need (%) Region: Pt n=105	Unmet Need (%) Region: Se n=30	Unmet Need (%) Population Size of Place of Residence*: <3000 inhabitants n=70	Unmet Need (%) Population Size of Place of Residence*: 3000–200,000 inhabitants n=159	Unmet Need (%) Population Size of Place of Residence*: >200,000 inhabitants n=126
Attitudes												
Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members/of health professionals												
28. Teachers, therapists, and doctors who listen to your views	12.7	12.8	12.3	13.4	16.1	10.2	25.0	9.6	13.3	14.3	14.7	9.5
42. Do students/colleagues/health care professionals have a positive attitude toward you?	4.5	5.1	2.3	8.9	5.7	4.6	8.3	2.9	6.7	7.1	5.7	2.4
53. Do staff at college/placement/work understand your needs (medical condition)?	13.0	11.3	9.7	16.5	18.3	9.4	20.8	6.7	18.5	17.1	13.0	7.9
Individual attitudes of immediate family members/of extended family members/of friends												
41. Do family and friends have a positive attitude toward you?	1.5	4.5	1.8	4.4	1.1	1.8	0.0	6.7	0.0	0.0	3.1	4.0
45. Do your family and friends encourage you to do things and to try things out?	6.6	8.3	6.4	8.9	4.5	2.8	8.3	15.2	3.3	5.7	9.5	5.6
Individual attitudes of strangers												
43. Do the general public/strangers have a positive attitude toward you?	28.6	25.3	26.0	28.9	26.7	26.2	0.0	34.3	28.6	30.0	25.9	26.2
Services, systems, and policies												
Social security services, systems, and policies												
33. Financial support/grants from the government/council for: Equipment such as wheelchairs, communication aids, hoists, bathing aids, etc.	9.5	13.4	10.5	12.4	19.3	2.7	8.3	14.3	10.0	10.0	14.5	7.9
34. Financial support/grants from the government/council for: Home modifications	21.0	18.5	11.4	33.6	20.5	11.8	29.2	29.5	6.7	18.6	25.2	14.3
35. Financial support/grants from the government/council for: A personal assistant	11.5	19.7	6.4	29.2	11.4	15.5	8.3	23.8	0.0	14.3	19.5	10.3
36. Financial support/grants from the government/council for: Travel/transport	21.0	28.7	17.3	35.8	29.5	14.5	29.2	34.3	6.7	30.0	25.8	19.8

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37. Financial support/grants from the government/council for: Leisure activities/holidays	25.5	33.3	18.7	45.3	33.3	20.9	33.3	36.2	16.7	25.7	37.1	20.6
Associations and organizational services, systems, and policies												
29. Support groups in your area	20.1	16.1	16.4	21.5	13.6	19.4	34.8	19.0	13.3	18.6	20.9	15.1
General social support services, systems, and policies												
30. Counseling services	17.6	17.3	19.2	14.7	13.8	19.1	30.4	18.1	10.0	14.3	18.9	17.5
Health services, systems, and policies												
24. Specialized therapy services such as: Physiotherapy	18.5	13.5	16.8	15.4	17.0	6.4	29.2	22.9	16.7	12.9	18.2	15.9
25. Specialized therapy services such as: Speech therapy	16.6	14.6	12.3	21.3	14.8	10.1	25.0	21.0	13.3	20.0	18.2	10.3
26. Specialized therapy services such as: Occupational therapy	14.7	20.4	15.1	20.6	18.6	14.7	20.8	22.9	0.0	17.1	17.6	16.7
27. Specialized therapy services such as: A specialist doctor who knows about your condition	12.5	13.4	10.5	16.8	6.8	21.8	20.8	4.8	20.0	14.3	13.8	11.1
Communication services, systems, and policies												
46. Do you have access to social media? (eg, texting, FB, Twitter)	26.1	33.3	17.4	48.5	27.6	32.1	25.0	30.5	23.3	38.6	28.5	25.4
58. Is information about services easy to understand?	38.7	42.6	30.3	56.6	46.6	48.6	41.7	28.6	32.1	45.7	38.9	38.9
59. Is information about activities in your area, eg, cinema, easy to understand?	23.4	35.3	19.7	43.0	36.4	34.9	16.7	22.1	14.3	35.7	27.2	26.2
60. Is there information about accessibility of places in your area?	48.4	58.9	44.2	66.7	42.5	45.6	62.5	64.8	62.5	55.7	57.8	41.3
61. Is information about employment/education available to you?	41.4	52.6	31.8	71.4	46.9	40.9	50.0	51.0	46.2	47.1	50.0	39.7
Open space planning services, systems, and policies												
19. Accessible car parking in places where you need to park	23.6	29.9	15.9	43.4	31.8	21.1	37.5	28.6	13.3	31.4	27.2	23.0

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Transportation services, systems, and policies												
20. Adequate public transport (buses/trains/ taxis)	16.6	22.4	12.3	30.1	14.8	17.6	45.8	18.1	20.0	27.1	17.6	15.9
21. Accessible public transport (buses/trains/ taxis)	17.1	24.5	11.0	35.6	18.2	16.8	41.7	19.0	26.7	24.3	20.8	16.7
Civil protection services, systems, and policies												
55. Is public transport safe?	28.2	37.2	22.5	48.1	23.3	32.4	54.2	32.4	39.3	37.1	32.9	27.8
56. Is your local area safe?	9.6	8.9	6.4	14.0	5.7	10.9	12.5	9.5	10.3	8.6	10.2	8.7
Education and training services, systems, and policies												
54. Does your college/employer/day placement provide for your needs?	20.6	16.4	16.7	22.2	20.3	15.0	21.7	20.0	22.2	20.0	20.5	14.3
Understand and be understood												
47. Do your family and friends understand your speech/way of talking?	9.1	11.7	5.5	18.0	11.6	7.5	16.7	12.4	3.3	12.9	8.2	10.3
48. Do people around you (personal assistant/ students/colleagues/ health care professionals) understand your speech/way of talking?	17.2	16.1	7.8	31.3	17.6	16.5	16.7	16.2	16.7	22.9	14.6	15.1
49. Do the public/strangers understand your speech/way of talking?	35.9	35.5	19.7	61.5	30.2	27.8	41.7	42.9	50.0	41.4	35.4	31.7
50. Do your family and friends communicate in a way that is easy to understand?	3.0	5.1	2.3	6.6	1.1	2.7	4.2	6.7	6.9	1.4	4.4	4.8
51. Do people around you (personal assistant/ students/colleagues/health care professionals) communicate in a way that is easy to understand?	7.1	9.6	3.2	16.3	4.5	10.0	4.2	9.6	10.7	12.9	7.0	7.1
52. Do the public/strangers communicate in a way that is easy to understand?	27.8	25.2	17.8	41.0	23.9	31.2	16.7	28.2	20.7	31.4	26.8	23.8

Abbreviations: De, Germany; FB, Facebook; Fr, France; GMFCS, Gross Motor Function Classification System; It, Italy; Pt, Portugal; Se, Sweden; SPARCLE3, Study of PARticipation of children with Cerebral palsy Living in Europe — third wave.

* Two young adults did not fulfil their place of residence.

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Conclusion

The EAEQ is an original measurement tool whose use could help accelerate the integration of young adults with CP into society by identifying the environmental changes that would improve their life.

Key Words

Cerebral palsy; Young adults; Environmental questionnaire; Environmental unmet needs; International Classification of Functioning; Disability and Health

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II. PARTIE VALORISATION DES RÉSULTATS DE LA RECHERCHE

CONSIGNES DE REMPLISSAGE

Pour rappel, la politique de Science ouverte à l'IReSP vise à ce que les coordonnateurs des projets financés par l'IReSP déposent en priorité les articles scientifiques issus des projets de recherche financés dans des revues ou ouvrages en accès ouvert. À défaut, le bénéficiaire ainsi que les équipes participant à la réalisation du projet s'engagent à déposer dans une archive ouverte publique comme HAL. **L'article 30 de la Loi pour une République Numérique fixe comme délai maximum d'embargo** :

· **6 mois** pour les publications dans le **domaine des sciences, de la technique et de la médecine (STM)**.

· **12 mois** pour les publications dans le **domaine des sciences humaines et sociales (SHS)**.

Pour les publications non accessibles en accès ouvert, merci d'indiquer les raisons n'ayant pas permis de favoriser cette démarche.

1. Publications scientifiques

1. Liste des articles et communications écrites

Articles scientifiques

- Vidart d'Egurbide Bagazgoïtia N, Perret C, Himmelmann K, Thyen U, Ehlinger V, Duffaut C, Arnaud C, Sentenac M. Employment and higher education in young adults with cerebral palsy: a cross-sectional analysis of the SPARCLE study. BMJ Public Health 2023;1:e000141. https://doi.org/10.1136/bmjph-2023-000141
- Guyard A, Fauconnier J, Muehlan H, Cytera C, Markwart H, Himmelmann K, Schmidt S, Duffaut C, Arnaud C, Thyen U. Differences in participation between young adults with cerebral palsy and their peers: A cross-sectional multicentre European study. Disabil Health J 2024;17(2):101554. https://doi.org/10.1016/j.dhjo.2023.101554
- Perret C, Alvarelhão J, Pennington L, Ehlinger V, Duffaut C, Arnaud C, Vidart d'Egurbide Bagazgoïtia N. Assessing the Adequacy of the Physical, Social and Attitudinal Environment to the Specific Needs of Young Adults with Cerebral Palsy: Development and Description of the European Adult Environment Questionnaire. Arch Phys Med Rehabil 2024; 11:S0003-9993(23)00693-7. https://doi.org/10.1016/j.apmr.2023.11.012
- Muehlan H, Alvarelhao J, Arnaud C, Cytera C, Fauconnier J, Himmelmann K, Marcelli M, Markwart H, Rapp M, Schmidt S, et al. Satisfaction with health care services in young people with cerebral palsy in the transition period: results from a European multicenter study. Front Med 2024; 11:1306504. https://doi.org/10.3389/fmed.2024.1306504
- Rioual J, Perret C, Arnaud C, Vidart d'Egurbide Bagazgoïtia N. Unmet environmental needs and unmet healthcare needs in a population of young adult with cerebral palsy: what the SPARCLE study tells us. Front Rehabil Sci 2024 ; 2:5:1294999. https://doi.org/10.3389/fresc.2024.1294999

2. Liste des thèses démarrées, en cours et/ou soutenues en relation directe avec le projet

Perret C (sous la direction de Arnaud C et Vidart d'Egurbide Bagazgoïtia N). Inadéquation de l'environnement : Mesure et impact sur la participation de jeunes adultes avec paralysie cérébrale. Soutenance prévue décembre 2024. Thèse financée par une bourse doctorale du Ministère de la Recherche et de l'Enseignement Supérieur.

3. Liste des séminaires ou colloques en rapport avec le projet financé auxquels vous avez participé et/ou que vous avez organisés durant la période concernée

- Vidart d'Egurbide Bagazgoïtia N, Perret C, Himmelmann K, Thyen U, Ehlinger V, Duffaut C, Arnaud C, Sentenac M. Higher education and employment in young adults with cerebral palsy: an analysis of the SPARCLE study. 34th EACD (European Academy of Childhood disabilities) meeting, 18th-21st May 2022, Barcelona (Spain). Communication orale
- Arnaud C, Vidart d'Egurbide Bagazgoïtia N, Perret C. Environnement, accès à l'emploi et qualité de vie des jeunes adultes avec paralysie cérébrale : exemples d'utilisation de registres de handicap pour documenter des questions sociétales. Journées de la FEDHRA (Fédération pour la recherche sur le handicap et l'autonomie), 17-18 Novembre 2022, Brest (France). Communication orale
- Vidart d'Egurbide Bagazgoïtia N. Emploi et Etudes supérieures des jeunes adultes avec paralysie cérébrale. Conférence ALTER Disability Research, 28-30 Juin 2023, Paris (France). Communication orale
- Perret C. Adéquation de l'environnement aux besoins spécifiques des jeunes adultes avec paralysie cérébrale : Donnée de l'étude européenne SPARCLE3. Conférence ALTER Disability Research, 28-30 Juin 2023, Paris (France). Communication orale
- Vidart d'Egurbide Bagazgoïtia N on behalf of the SPARCLE group. Results from a European multicenter study: SPARCLE 3. Plenary meeting of Surveillance of Cerebral Palsy in Europe (SCPE), 19th-20th February 2024, Lisbon (Portugal).
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- Perret C, Ehlinger V, Shourick J, Delobel M, Himmelmann K, Thyen U, Vidart d'Egurbide Bagazgoïtia N, Arnaud C. Exploring the influence of physical, social and attitudinal environment on the participation of adults living with cerebral palsy. 36th EACD (European Academy of Childhood disabilities) meeting, 29th May-1st June 2024, Bruges (Belgium). Communication orale

4. Liste des éventuelles missions à l'étranger effectuées dans le cadre du projet

Préciser la date, le lieu, l'objet, les équipes ou autres acteurs rencontrés
Aucune

2. Communications autres

Lister les communications autres qu'académiques. Il peut s'agir de site internet, interview, questionnaire, forum, plaquette de présentation, capsule vidéo, …

Aucune

FICHE A RENSEIGNER

Publications scientifiques

Ajouter tous les liens URL des publications, si possible.
Merci de préciser quand l'article n'est pas disponible en accès ouvert, le cas échéant, joindre l'article en format PDF.

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- …

Communications au grand public

Ajouter les liens URL et/ou joindre le fichier en annexe, si possible

- …