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Educational intervention for parents of adolescents with chronic illness: a pre-post test pilot study

Abstract

Objective: This pilot experimental study tested the feasibility and intended effect of an educational intervention for parents to help them assist their adolescent child with chronic illness (CI) in becoming autonomous.

Methods: A two-phase pre-post pilot intervention study targeting parents of adolescents with CI was conducted. Parents were allocated to group 1 and 2 and received the four-module intervention consecutively. Intended effect was measured through online questionnaires for parents and adolescents before, at 2 months after, and at 4-6 months after the intervention. Feasibility was assessed through an evaluation questionnaire for parents. Results: The most useful considered modules concerned the future of the adolescent and parents and social life. The most valued aspect was to exchange with other parents going through similar problems and receiving a new outlook on their relationship with their child. For parents, improvement trends appeared for shared management, parent protection, and self-efficacy, and worsening trends appeared for coping skills, parental perception of child vulnerability, and parental stress. For adolescents, improvement trends appeared for self-efficacy and parental bonding and worsening trends appeared for shared management and coping skills.

Conclusion: Parents could benefit from peer-to-peer support and education as they support the needed autonomy development of their child. Future studies should test an online platform for parents to find peer support at all times and places.

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Introduction

Approximately 10% of adolescents suffer from a chronic illness (CI), limiting their daily activities (1). When children with CI reach adolescence, parents are generally not ready to deal with the specificities of this period as the struggle for autonomy and greater responsibility for behavior is accentuated by the limits implied by the CI and associated treatments (1). Parents often do not know what degree of autonomy to give their adolescent (2), and overprotection is a common reaction (3). For parents who have always played a crucial role in the management of their child's health and life in general, it is often difficult to adapt to potential changes during this period. The main difficulty lies in how to maintain a supervisory role while supporting young people's emerging abilities to independently manage their health (4).

The child-parent relationship has a critical influence on the child's ability for self-management (5). Yet, while transition programs have often been put in place for adolescents (6, 7), transition from a parent's perspective is often overlooked. Moreover, most interventional studies have targeted children and adolescents (8, 9), but few have included parents. Studies targeting parents (10–12) concerned children rather than adolescents, did not address the question of autonomy, or were disease specific, thus not addressing the general concerns of parents of adolescents with CI. In addition, the main focus of many interventions was on disease management, with less attention being paid to the psychosocial aspects of living with a CI (8). Therefore, parents could benefit from support during this difficult period in order

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for them to better lead their adolescents on the road to autonomy.

The needs of parents of adolescents with CI have been identified. A qualitative study conducted to determine the challenges that adolescents with CI and their parents faced on the route to autonomy (13) showed that parents lacked tools to deal with the difficulties related to their child's autonomy and self-management and often did not know what difficulties were attributed to the illness or to the adolescence process. Similarly, Sawyer and Aroni (4) found that parents require guidance as to how their behavior can facilitate or hinder the emerging capacity for self-care in adolescents with CI. Parents' coping skills also need to be developed, as they are significantly associated with lower levels of parental stress (14) and fewer depressive symptoms (15). Finally, interventions should include fathers as well as mothers (16), especially when facing adherence and self-management problems (17).

Both adolescents with CI and their parents are vulnerable populations as they often experience limited sources of psychosocial support. Standard practice includes follow-up consultations and therapeutic education for patients but does not specifically target parents. Education and early preparation of parents may help the transition of treatment responsibilities and self-management (18). A longitudinal study (19) has shown the importance of maintaining parental involvement throughout adolescence to contribute to better adherence and self-efficacy. In fact, support provided to parents can impact on their own well-being, which, in turn, can positively influence their children's health outcomes as well as the well-being of the whole family.

The aim of this pilot experimental study was to test the feasibility and intended effect of an educational intervention for parents to help them assist their adolescent child with CI in becoming autonomous.

Material and methods

We conducted a two-phase pre-post pilot intervention study targeting parents of adolescents with CI.

Participants

With the use of a noncategorical approach to CI (20), all parents who met the eligibility criteria were recruited in five specialized pediatric clinics of a tertiary referral Hospital in Western Switzerland: gastroenterology, diabetetology, rheumatology, pneumology (cystic fibrosis only), and hemato-oncology (sickle cell disease only), between November 2012 and February 2013.

Inclusion criteria consisted of being the mother or father of a 10–14-year-old adolescent suffering from a CI requiring continuous medical management since at least 1 year and being fluent in French. Stepmothers/stepfathers could participate if they took care of the child with CI regularly. Exclusion criteria consisted of parents of adolescents with CIs that implied a mental or severe physical handicap as chances to become autonomous are fairly limited. Additionally, only one parent per family could participate to [1] avoid imbalance between two- and single-parent families, [2] avoid conjugal issues to take over, and [3] include as many families as possible and because [4] research has shown that when only one parent changes parenting style, effects on the child still occur (21). The same parent had to take part in the whole intervention.

Following ethics committee approval, the head of each clinic provided a list of names and postal addresses for patients who met inclusion criteria. A letter cosigned by the head of each clinic and the principal investigator (PI) describing the study and inviting parents to participate was sent out to 253 families. We contacted as many families since we expected a low participation rate knowing that parents of children with CI are often solicited for medical treatments and research, many live far away, and Swiss winters can be harsh and discourage people from going out in the evenings. The opt-out option was chosen: Parents were informed that they would be contacted by telephone unless they indicated that they did not wish so by contacting the PI. Details on recruitment process are given in the flow diagram (Figure 1).

Two groups of parents were constituted in order to have small enough groups to allow interaction and received the intervention consecutively. Recruited parents were allocated to group 1 (G1) and 2 (G2) according to their availability (Table 1). The final sample included 26 parents.

Intervention

We developed the intervention according to the results of our qualitative study (13), and it was grounded in the principles of participatory training (22). The Social Cognitive Theory (23, 24) served as the theoretical framework as parents learned from each other's experience.

The intervention consisted of four 2-h modules given in the evening during 2 months covering different themes: [1] promoting shared management, [2] enhancement of social life, [3] the future of the adolescent and the parents, and [4] a wrap-up session to discuss improvements in parents' lives. Objectives and activities were carefully planned for each module (Table 2). As much as possible, the intervention was given identically to G1 and G2. A little snack was offered at the end of each module to give parents time for informal talk. At the end of the four modules, parents were given a brochure containing a summary of discussed themes, difficulties, and solutions, as well as a list of resources they can address. Parents who missed a module were invited to come earlier before the following session to receive a short catch-up session.

Outcome measures

The primary outcome measure, parent-child shared management, was assessed in the parent and adolescent questionnaires using a 12-item shared management scale (25). An example of an item for parents was "I want my child to take on more responsibility for the care of his/her chronic illness." For adolescents, items were transferred

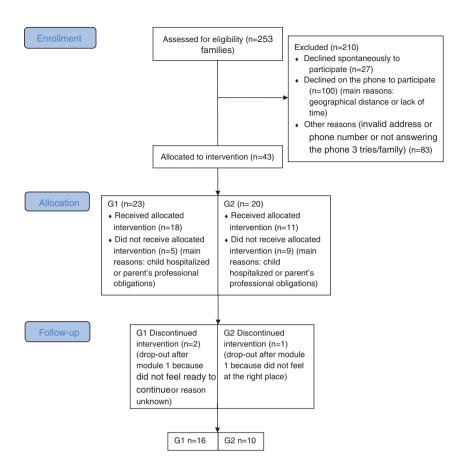


Figure 1 Flow diagram of the intervention.

into the first person, such as "I can identify several things I can do to manage my chronic illness care now or in the near future." Responses ranged from strongly disagree (1) to strongly agree (5) for each item. For analysis, items were grouped into three subscales: parent/adolescent desires, current knowledge, and current actions. Total and subscale scores were computed using the mean of individual questions for each subscale and the mean of all questions for the total score.

Parental and adolescent self-efficacy was measured through the Self-Efficacy for Managing Chronic Disease Scale (six items) (26). While items were the same for parents and adolescents, the latter responded for themselves, and the former responded for their child. Responses ranged from 1 (not at all confident) to 10 (totally confident).

To evaluate coping skills among parents and adolescents, we used the Family Crisis Oriented Personal Evaluation Scale (15), a 29-item self-report tool consisting of statements starting with "When we face problems or difficulties in our family, we respond by..." and continuing, for instance, with "sharing our difficulties with relatives." Respondents strongly disagreed to strongly agreed on a 5-point Likert-type scale. The overall coping score, combining five subscales (acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal), was used in our analysis.

For the parent questionnaire, we used the Parental Bonding Instrument-Brief Current form (PBI-BC) (27) intended to measure perceptions of current parental characteristics. The PBI-BC validated scale consists of eight items inquiring into parental characteristics over the previous 3 months.

For the adolescent questionnaire, the Parental Bonding Instrument (PBI) was used (28). The PBI consists of 25 items divided into two scales termed 'care' (12 items) and 'overprotection' (13 items) measuring fundamental parental styles as perceived by the child. Adolescents completed the measure once for each parent.

Parental perceptions of child vulnerability were measured for parents only using the Child Vulnerability Scale of Forsyth et al. (29). This 12-item instrument included statements such as "In general my child seems less healthy than other children," to which parents strongly disagreed to strongly agreed on a 4-point scale. A score of 10 or above was used as the cutoff point to categorize perceived vulnerable subjects.

Parental stress was measured using the Parental Stress Scale (PSS) (30). The PSS consists of 14 items assessing perceived stress as a parent during the past month, such as "In the last month, how often have you felt nervous and 'stressed?" Answers ranged from never to very often on a 4-point scale.

Demographic and clinical variables included personal characteristics (age, relation to child [parent/stepparent], relationship with other parent, professional activity, and type of CI), time since diagnosis, and visibility of the CI. Condition severity was assessed through the Severity of Illness Scale (25), a six-item scale measuring the degree of limitation in daily life caused by the CI and number of treatments taken. Parenting style was evaluated only among adolescents through four items (31): two items assessing parental monitoring and two items assessing parental rules and given support. For each statement, responses ranged from strongly agree to strongly disagree on a 5-point scale.

Table 1 Description of the study sample (n=26).

Parent	rent Child's age		Child's CI	Missed modules	
Group 1 (n=16)					
Mother	10	Male	Diabetes	None	
Mother	14	Female	Diabetes	Module 1	
Mother	12	Male	Diabetes	None	
Mother	12	Male	Diabetes	None	
Mother	11	Female	Diabetes	Module 3	
Mother	12	Male	Diabetes	None	
Mother	11	Male	Diabetes	None	
Mother	11	Male	Diabetes	None	
Mother	10	Male	Diabetes	None	
Mother	13	Male	Diabetes	None	
Mother	13	Male	Cystic fibrosis	None	
Mother	14	Male	Cystic fibrosis	None	
Mother	11	Male	Cystic fibrosis	Module 4	
Father	14	Male	Diabetes	Module 3	
Father	12	Male	Diabetes	Module 3	
Father	13	Male	Cystic fibrosis	None	
Group 2 (n=10)					
Mother	12	Male	Diabetes	None	
Mother	10	Male	Diabetes	Module 2	
Mother	13	Male	Sickle cell disease	Module 4	
Mother	14	Female	Cystic fibrosis	None	
Mother	12	Male	Juvenile rheumatoid arthritis	None	
Mother	10	Female	Juvenile rheumatoid arthritis	Module 4	
Father	11	Male	Diabetes	Module 3	
Father	11	Male	Diabetes	None	
Father	13	Female	Sickle cell disease	Module 4	
Stepfather	14	Male	Sickle cell disease	None	

 Table 2
 Summary of the content of the intervention.

	Objective(s)	Content of modules
Module 1:	To help parents find ways to	Address three aspects of shared management:
Promoting shared	assist their child in the medical	– The medical follow-up
management	shared management of his/	- Medication intake
	her CI	 Parents' ambivalence regarding child's autonomy in medical handling: wanting their child to be autonomous while having difficulty trusting as health is at stake
Module 2:	To help parents find solutions	Address two aspects of adolescent's social life:
social life enhance	and let go so their child can enhance his/her social life in a secure way	 Going out and doing activities on his/her own, which implies the parents to set limits, trust their child, and implement strategies to enhance autonomy despite the worries linked to the CI
		 Building friendship and social networks, not getting excluded by peers due to the physical limits of the CI, or building romantic relationships similar to their same-age peers, sexuality
Module 3:	To help parents imagine a future	– Discuss parents' concerns about the future of their child in terms of their
The future of	with an empty nest and give	professional life (school, professional training, finding a career adapted to the
adolescent and	them concrete tools for this	limits of the CI, etc.) or their health (including secondary effects of treatments,
parents	soon-to-come step	long-term effects of CI)
		 Discuss the future of the parents as their immediate implication will soon change (as their child leaves home, studies, starts working etc.)
Module 4:	To evaluate the intervention by	– Discuss remaining questions or difficulties that have not been solved
Wrap-up	discussing the improvements it has brought in the parents' lives	 Discuss improvements that have been made in their relationship with their child since the beginning of the intervention: what has worked

Questionnaires

To measure the intended effect of the intervention, two online questionnaires were built with the described measures: one for the participating parent and one for their child with CI. Questions that did not have a French version were translated using a standard translation practice (32): Authors were contacted for permission to use and translate their questions; the PI translated the questions into French; a native English speaker external to the study back-translated the questions; and both versions of the English questionnaires were revised by members of the research group and discrepancies were discussed until reaching consensus. Finally, the French questionnaires were tested for comprehension by seven adolescents aged 11-19 years and four parents of adolescents. A few minor changes were brought to the final versions according to the pretests.

Parents and adolescents were invited to complete the questionnaires at three time points: [1] right before the intervention started (T0), [2] at 2 months, right after the end of the intervention (T1), and [3] at 6 and 4 months after the end of the intervention for G1 and G2, respectively (T2).

Questionnaires were filled out online in about 30 min. The URLs were sent to participants by e-mail, asking parents to pass it on to their child to fill out alone. Questionnaires were filled out anonymously, but respondents entered a personal code to match them between waves.

Data analyses

We merged responses from both groups for analysis to increase sample size. We used the signed-rank test (33) to compare first the distribution of the answers between T0 and T1 (once with the whole sample and once only with T2 respondents) and second between T0 and T2. The null hypothesis was that the distribution was similar in both occasions. This nonparametric test for paired data was preferred to the most usual Student's t-test because of the small sample size. Positive values of the test indicate a trend toward higher values of the tested scale.

Feasibility evaluation

In order to evaluate the feasibility of the intervention, all participating parents filled out a two-page evaluation questionnaire at the end of module 4. It included seven questions (three closed and four open ended) regarding usefulness and appreciation. Data were analyzed qualitatively using a thematic analysis method.

Results

Parents

Whether for G1 or G2, no parent missed more than one module (Table 1). Except for the last module, all parents who did were given a short catch-up session.

Written evaluations of the intervention suggested that the modules concerning the future of the adolescent and parents and social life were considered as the most useful. In particular, module 3 on the future had the most impact as parents had not started thinking about these issues yet. The most important positive aspect of the intervention stated by the participants was the possibility to exchange with other parents who were going through similar problems. Intervention participation highlighted a common feeling of loneliness when facing both the problems linked to adolescence and to the CI. Moreover, parents valued the fact that the intervention brought them a new outlook on their relationship with their child and helped them take a step back and put their concerns into perspective. Negative comments concerned mainly practical aspects such as schedules, lack of explanations regarding unknown illnesses, and the fact that only one parent per family could participate.

Questionnaires' response rates for parents were 83.5% at baseline, 69.2% at immediate postintervention, and 46.2% at 4 (for G1) or 6 (for G2) months postintervention.

Regarding intended effect, none of the outcome measures were statistically different between T0 and T1 or between T0 and T2. Nonetheless, parent-child shared management and parent protection scores increased from TO to T1 and even more from T0 to T2, although not reaching significance. For parental self-efficacy, scores worsened between T0 and T1 but improved between T0 and T2. In contrast, coping skills, parental perception of child vulnerability, and parental stress showed improvement trends at T1 but worsening trends at T2 when compared with baseline (Table 3).

Adolescents

Adolescents' response rates decreased from 61.5% at baseline to 46.2% at immediate postintervention and 26.9% at 4 (for G1) or 6 (for G2) months postintervention (Table 3).

A worsening trend at T1 and an improvement trend at T2 were found in adolescents' self-efficacy but did not reach significance. However, we found a worsening trend of shared management and, like for parents, a worsening trend for coping skills at T2. As for parental bonding, the total scale showed an overall improvement trend at T1 and T2 (Table 4).

Discussion

The evaluation of the intervention put forward an overall positive appreciation of the four modules. It thus seems

Table 3 Parents: comparisons T0-T1 and T0-T2.

Scale	T0–T1 (all) (n=14 or 15)		T0–T1 (only those who also responded at T2) ($n=11$ or 12)		T0-T2 (n=11 or 12)	
	Diff.	p-Value	Diff.	p-Value	Diff.	p-Value
Parent-child shared management						
Total scale	0.33	0.74	0.51	0.61	1.46	0.14
Subscales						
Parent desires	0.13	0.9	-0.08	0.93	0.92	0.36
Current knowledge	1.43	0.15	1.63	0.10	1.66	0.1
Current actions	-0.55	0.58	-0.25	0.81	1.19	0.23
Parental self-efficacy						
Total score	-0.26	0.79	-0.39	0.7	1.46	0.15
Coping skills						
Total scale	1.03	0.31	0.62	0.53	-0.67	0.51
Subscales						
Acquiring social support	0.1	0.92	0.08	0.94	-1.49	0.14
Reframing	1.43	0.15	1.23	0.22	0.000	1.000
Seeking spiritual support	-0.32	0.75	-0.54	0.59	0.48	0.63
Mobilizing family to acquire and accept help	0.07	0.94	0.04	0.97	0.32	0.75
Passive appraisal	-0.29	0.77	-0.32	0.75	-1.49	0.14
Parental perceptions of child vulnerability						
Total scale	0.46	0.65	0.28	0.78	-0.56	0.58
Parent protection scale						
Total scale	0.47	0.64	1.44	0.15	0.56	0.57
Subscales						
Care items	0.92	0.36	0.33	0.74	0.38	0.71
Rejection items	0.1	0.92	0.13	0.9	-1.41	0.16
Control items	-0.25	0.8	1.49	0.14	-0.5	0.62
Autonomy items	0.3	0.77	0.5	0.62	1.55	0.12
Care-rejection	0.81	0.42	0.32	0.75	1.07	0.28
Control-autonomy	-0.31	0.76	0.64	0.52	-1.33	0.18
PSS						
Total scale	0.68	0.5	1.14	0.25	-0.55	0.61

Results from the signed-rank test. A positive difference means an improvement from T0 to T1 or from T0 to T2.

possible to conclude that the given intervention was feasible and successful and fulfilled a major concern for parents of adolescents with CI: exchanging with others who are going through the same and in turn changing their perspective on their situation. This is in line with the social cognitive theory applied as the premise for this intervention study (23).

Evaluation also stressed that one of the most appreciated modules was the one concerning the future of the adolescent and parents. This corroborates the results of our qualitative study (13), as the future was expressed by parents as a major preoccupation for them whether in terms of health or professional future. Indeed, it is known that adolescents with CI are at increased risk for poor educational, vocational, and financial outcomes as young adults (34) compared with their healthy counterparts. Hence, it appears crucial to discuss this aspect

since childhood as part of the global and routine process of transitional care planning. Extra guidance concerning aspects such as professional life choices could also be useful when reaching adolescence. However, this theme should be on the agenda early enough in order to contribute to the development of children with CI to their maximum potential (35).

Regarding feasibility of the intervention, two main aspects should be retained. First, participating in the intervention implied a lot of organization for parents to be free four evenings over a period of 2 months due to other life requirements. Therefore, conducting the intervention in 1 day deserves to be tested in the future, which can also avoid parents missing a module. Another solution to increase attendance rates could be to integrate parent groups in clinical practice (e.g., when taking time to accompany their child to consultation) instead of parents

Table 4 Adolescents: comparisons T0-T1 and T0-T2.

Scale	T0-T1 (all) (n=12)		T0-T1 (only those who also responded at T2) (n=7)		T0-T2 (n=7)	
	Diff.	p-Value	Diff.	p-Value	Diff.	p-Value
Parent-child shared management						
Total scale	0.2	0.85	-1.29	0.2	-0.25	0.80
Subscales						
Parent desires	-0.12	0.91	-0.86	0.39	-0.26	0.8
Current knowledge	0.43	0.66	-0.68	0.5	-0.6	0.55
Current actions	-0.91	0.36	-1.38	0.17	-1.26	0.21
Adolescent self-efficacy						
Total scale	-0.82	0.41	-0.51	0.61	1.27	0.20
Coping skills						
Total scale	0.91	0.37	0.76	0.45	-0.34	0.74
Subscales						
Acquiring social support	0.4	0.69	0.77	0.44	-1.19	0.23
Reframing	-0.12	0.91	-0.26	0.8	0.76	0.45
Seeking spiritual support	2.61	0.01	1.56	0.12	1.25	0.21
Mobilizing family to acquire and accept help	0.51	0.61	0.85	0.4	-0.78	0.44
Passive appraisal	-0.76	0.45	-0.26	0.8	-0.35	0.73
PBI						
Total scale	0.16	0.88	1.53	0.13	0.09	0.93
Mother: care	2.22	0.03	1.72	0.09	0.09	0.93
Mother: overprotection	-1.45	0.14	-1.03	0.30	-0.42	0.67
Father: care	-0.47	0.64	0.34	0.73	0.68	0.5
Father: overprotection	0.91	0.37	0.25	0.8	0.68	0.5

Results from the signed-rank test. A positive difference means an improvement from T0 to T1 or from T0 to T2.

having to take extra time off their often busy schedule. Second, some parents expressed disappointment because not both parents could participate in the intervention. This could be either because both are interested or in line with the findings from the qualitative study regarding important differences in perception between mothers and fathers (13). Thus, future studies should leave it open for both parents to participate in order to consider the whole parental dynamic.

Outcome comparisons between TO and T1 and between T0 and T2 showed a general improvement trend in parents' and adolescents' self-efficacy, shared management, and parents' protection. Overall, although these results do not reach significance due to the small sample size, these outcomes show encouraging trends toward improvement in the longer run among parents.

However, the fact that these outcomes do not show improvements before T2 suggests that parents need time to integrate and apply what they have learned during the intervention. In future intervention studies of this kind, outcomes should continue to be measured in the long run to assess if they have an effect over time taking into account adolescent development. This is in line with the findings of Barlow and Ellard (8) that longer-term studies are needed to determine whether the benefits of psychoeducational interventions on children with CI and their parents are ultimately maintained.

Other outcomes show the reverse trend, such as stress (for parents) and coping skills (for parents and adolescents). Although these results are not significant, it is not excluded that parental stress increases after the intervention because of new issues occurring in their mind. This might have been the case regarding module 3 on the future of their child, as these matters had not arose before. It could also have been the case regarding medication adherence since greater parental responsibility for treatment management has been shown to be associated with greater general parental stress (36). The intervention might have had a transitory crisis-effect, but which might be beneficial in the long-term by helping moving on to the next step. These advancements start showing at T2 and may rather be measurable later on. Hence, these results seem to indicate that the concerns brought up in the intervention should be discussed progressively throughout childhood into adolescence rather than abruptly when children with CI reach adolescence. These concerns should be part of a general process toward taking on autonomy.

Strengths and limitations

Several limitations warrant to be stressed. First, we had originally planned to block-randomize the recruited parents into intervention and wait-list control groups. However, parents were recruited from all over Frenchspeaking Switzerland, making it often difficult for them to get away for four evenings from their daily requirements. Consequently, priority of recruiting parents took over priority of strict randomization, and we decided to let the parents choose the session according to their availability. Consequently, participants in each group acted as their own controls, limiting the strength of the results. Second, although interaction during the modules was good and participation rate was fairly good, a small number of parents actually filled out the questionnaires, which led to little statistical power to detect an effect. Future studies should find ways through incentives or by having participants fill out questionnaires on the spot to increase participation. Third, adolescent questionnaire response rates were low, which made it difficult to determine if intervening only on parents can have an effect on adolescents. This, however, is less surprising as they did not take part in the intervention and difficulties in involving adolescents in research are well known (37). Future studies could also find incentives for adolescents to participate. Nevertheless, parents and adolescents had to fill out the same questionnaire several times, which took about 30 min each time. This might be discouraging and thus significantly decrease participation rates.

Despite these limitations, the major strength of this intervention study lies in the fact that parents from both groups were very much involved in all modules. Nobody missed more than one session, and those who did excused themselves and were given a short catch-up session before the next one. Participants valued their involvement and strongly expressed that exchanging with peers allowed them to acquire new views on their relationship with their adolescent child with CI and helped them put their problems and worries into perspective.

Conclusions

This intervention study put forward that parents could benefit from peer-to-peer support and education as they navigate and support the needed development of autonomy regarding CI self-management. Future studies should test if the effect of the intervention could be increased by including adolescents in it. Moreover, given that changes started to appear 4–6 months after the intervention, future studies should include measures of the effects over a longer period of time.

Given the strong satisfaction and support felt by parents of adolescents with CI when exchanging with peers who are undergoing similar experiences during this period often full of doubts and new challenges and the difficulties for some parents to participate in the intervention such as it was offered, building an online platform for parents could offer an interesting alternative. This can provide a way of finding peer support at all times and from anywhere.

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