"Let's talk about it", a mediation tool in couples, for adults living with cystic fibrosis

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Objectives

For adult patients living with cystic fibrosis, living as a couple is now almost as frequent as in general population. For patients living with CF, it is sometimes complicated to discuss certain issues and caregivers could help them.

Methods

- We developed a tool called "let's talk about it" which consists of a game board and 2 sets of 36 cards.
- Different domains are drawn on the board: (slide4)
 - familial life, professional or student life, leisure, care, future, relationship, home, and secret garden.
- Phrases or sentences extracted from a previous work with patients' interviews are written on each of the 36 cards.
- At the beginning of the session, the caregiver presents the support to the couple.
 - Then, each person thinks about the cards separately and puts the cards in the domains relevant to him.
 - Each person also thinks about what he wants to share with the partner. Next, there is a presentation of individual boards and development of a common platform.
 - The caregiver brings the two persons together and offers to talk about the cards they have chosen. He encourages each word within a framework of respect and trust, tries to raise reactions, the role of the caregiver is also to rephrase their words when it is necessary in order to ensure that the two partners are understood. He helps to synthesize similarities and differences.



Cards : French version

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	Si on en	parlait?) 🏯 < 🚥 🕢	*)	
	Document pour le couple	A .	» /	/
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	1		_	- '
	I	Il faut se battre un peu plus que les autres	1	
	2	C'est un combat de chaque jour	2	
	a 3	Ça fait beaucoup de contraintes	3	
Hereit	a 4	Heureusement qu'on s'aime	4	
Heureusement	5	Des petits brins de bonheur par-ci par-là	5	
qu'on s'aime	o	Ça m'angoisse	6	
	0 7	Pour moi, c'est complexe	7	
	8	L'argent, c'est vraiment une préoccupation	8	
	9	Ça fait mal	9	
A 11		II faut pouvoir assumer	10	
		Je vis au jour le jour	11	
joke		Que sera demain ?	12	
	3	On n'hésite pas à faire des projets	13	
	14	Je ne me sens pas compris(e)	14	
	15	J'ai besoin de comprendre	15	
	16	Je me sens diminué(e)	16	
	17	Je ne me sens pas à la hauteur	17	
	18	J'ai l'impression d'être un poids pour les autres	18	
	19	C'est beaucoup de fatigue	19	
	20	Il faut toujours tout programmer	20	
3	21	J'en ai marre	21	
	22	Je pense parfois à la mort	22	
Choisir d'avoir	23	J'aurais besoin qu'on en parle	23	
Choisir tant	24	Le regard des autres, c'est difficile	24	
Choisir de un enfant	2 25	Les rêves auxquels on doit renoncer	25	
	26	Estce qu'on parle des risques ?	26	
	27	La sexualité, c'est pas simple	27	
	32 28	Au fond, on est toujours tout seul	28	
	29	Un peu d'humour, ça aide	29	
	30	Je dors mal	30	
r I	31	Je revendique une vie normale	31	
	32	Choisir d'avoir un enfant	32	
	33	La greffe, c'est l'inconnu	33	
	34	Une nouvelle vie avec la greffe ?	34	
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		×	6	
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English version

1	You have to fight a little more than others	2	It 's a daily battle		
3	That's a lot of constraints		fortunately we love each other		
5	Small bits of happiness here and there		It frightens me		
7	For me, it is complex		Money is a realconcern		
9	It hurts		You must be able to assume		
11	I live one day after the other		What will be tomorrow?		
13	we do not hesitate to make plans		I do not feel understood		
15	I need to understand		I feel diminished		
17	I don't think I am up to the challenge		I feel like a burden on the others		
19	It is exhausting		We should always plan		
21	I'm sick of it		I sometimes think about death		
23	I would need to talk about it		the look of others is difficult		
25	Dreams that we must give up		Are we talking about the risks?		
27	Sexuality is not easy		basically, we're always alone		
29	A bit of humor helps		I sleep badly		
31	I claim a normal life		Choosing to have a child		
33	Transplantation is the unknown		A new life with the transplant?		

Conclusion

"let's talk about it "is a support which improves communication between two adults living as a couple. It may be also used for a better communication between parents of a cystic fibrosis child, between parent and adolescent and so on.

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