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Using an e-health tool for childhood obesity follow-up care: issues in health care pathway

Introduction: the specific care model of childhood obesity and its coordination issues at the local scale

As chronic diseases occupy an increasingly important position in the health area, health systems must find some other models to take care of these numerous new patients. Among them, childhood obesity is a special matter, as it occurs in the young years, but continues into adulthood. Actually, up to 70% of obese teenagers stay obese when they grow up (Haute Autorité de Santé 2011). As a reminder, according to World Health Organization, obesity and overweight are abnormal or excessive fat accumulation that may impair health (Organisation Mondiale de la Santé, s. d.). To measure it during childhood you have to calculate the Body Mass Index (BMI) and to report it on the corpulence curve, so you can see if the kid's weight crosses the IOTF 30 line,¹ depending on the kids' age. The significant prevalence of childhood obesity² leads to some reactions from health authorities (Haute Autorité de Santé 2011). They develop some actions on prevention along with care, especially with the Nutritional Health National Program, or with the Obesity Plan. For example, the Health High Authority made recommendations for the follow-up of childhood obesity (Haute Autorité de Santé 2011). Care is divided in three resorts depending on the complexity of the kids' situation. The first one is based on the general practitioner, helped by another professional if needed (such as a dietician or a psychologist). The second one is a multidisciplinary care, with several private professionals. It must be used if the kid is still gaining weight after the first step of care, or if he is in a difficult situation (especially in his family). The third and last resort is necessarily based on a specialized and multidisciplinary team help. These professionals can propose hospitalization or an aftercare and rehabilitation center. The common point is that all these steps must be based on the patient's therapeutic education (PTE) principles. Therapeutic Education Programs represent a specific model of care, based on patients' needs (Haute Autorité de Santé 2007). During these programs, different professionals work together to understand the patient's needs, and his own goals. Then they provide

1 The International Obesity Task Force is the international reference for overweight and obesity limits.

2 In France, 17% of children aged 6 to 17 are overweight and 4% of the same age children are obese.

specific education to improve the patient's autonomy and to help him customize his care to achieve his goals. This care organization in the territory can be difficult. To improve childhood obesity care management, a regional network was designed, the RéPPOP (childhood obesity prevention and care network). It is a city-hospital network, meaning one of the RéPPOP's goals is to coordinate care between hospitals and private professionals. The other focuses of the RéPPOP are to support treatment access for every family, to offer continuity of care and to promote a multidisciplinary approach (RéPPOP, s. d.). To comply with these aims, they develop lots of tools for the care, as well as a therapeutic education program inside the children hospital.

MyMouv': an e-health tool as an answer to the lack of coordination and motivation

According to their expertise, one of the ground issues the RéPPOP's members highlight about care is the lack of continuity in physical activity follow-up: kids are followed by lots of different professionals (doctors, sport teacher, physiotherapist, etc) in different institutions (aftercare and rehabilitation centers, hospitals, sport clubs, etc). There is currently no link between all these professionals and the children have to start from the beginning with each one of them. Another issue they often talk about is the patients' lack of motivation to practice a physical activity at home.

Thus the RéPPOP's coordination team decided to design a specific e-health tool: MyMouv'. This device first consists in a smartphone application for the patients, so they can enter some anthropometric data such as their weight, size, BMI. They can also enter their own physical activity goals and make self-assessment of their practice with imaged scales. The application also proposes some challenges depending on the sport profile the patient chose at the beginning ("I want to be fitter", "I want to have more muscles", etc.). They can follow their progression with graphics. The device also consists of a web platform, for the professionals, so they can follow the activity of the patient, and increment the patient's file with their results, but they can also include their reports about the care. A messaging service allows patients and professionals to communicate. The development of this tool went through three stages over the course of three years. Firstly, the conception (designing) of MyMouv' by the members of the coordination team. To construct the specifications, they conducted some focus groups with patients and professionals so they could better understand their needs. Then, the IT development was made in collaboration with information technology engineers, from spatial medicine, specializing in e-health. And finally, the test phase began with a test version of the device. The coordination team asked some sport teachers³ to try this device with their patients, in real care conditions.

Research problem and methodology

Our study focuses on this development process, from the conception to the test phase. We wanted to understand how an e-health tool can be integrated into a specific health model, like the childhood obesity care pathway. Our first research problem

³ Around twenty sport teachers were asked, but only six tried the device.

was: what are the issues surrounding the development of MyMouv' in the health care pathway? Obviously, choosing to develop an e-health tool is a decision took in a specific context regarding specific issues, as this device questions in a frontal way the impact of e-health on the health care pathway, specifically with children. We also wanted to know what are the engagement and coordination modes during this development? In order to do this we borrow the notion of "commitment" from Becker (2006). His definition explains the coherent trajectories of professionals' activities, which are based on the realization of a subsidiary bet: that the use of MyMouv' can help them following their interest, which is to improve the care. Being committed in the design and the use of this tool depends on different factors that we wanted to highlight. First, the effects of socialization influence the actors' approaches of this tool (Darmon 2016). Second, the practices also depend on the situation, and especially on the coordination modes (Dodier 1993). We consider that human actors, like ground professionals, patients, the coordination team, and non-human actors like e-health tools, evolve in a socio-technical network (Callon, Ferrary 2006). It is important to know who the involved actors are, how they are involved in the process, and also how they can be recruited, so that we understand how they can be resources or constraints (Akrich, Callon, Latour 2013). That is why studying the issues and the engagement modes can help us understand the ways of introducing e-health in a specific health model. We will demonstrate that the minimalist coordination modes between the actors during each step of the development did not allow a smooth integration of MyMouv' in the users' practices.

This survey is based on ethnographic observations (150 hours) made inside the RéPPOP's coordination team during various working times concerning the development of the device and setting up (meetings, conversations with adapted physical activities teachers, etc.). As well as semi-structured interviews (32) conducted with four RéPPOP members, two IT engineers and nine adapted physical activities teachers tested this device. Some of these interviews were reproduced during the different development stages.

Results

Designing MyMouv': hopes and difficulties surrounding the tool's conception

First, we will describe the hopes and difficulties surrounding the conception of MyMouv', as it provides numerous questions in the introduction of an e-health tool in the actual childhood obesity care model.

Using digital technology in the follow-up of obese children can be seen as a paradox. The coordination team actually highlight that one of the most important problems in the kids' behaviors is that they overuse screens, of all types like mobiles, television, tablet, etc. This intense consumption leads to a sedentary lifestyle and a lack of physical activity. MyMouv' intends to change those behaviors, but it puts children in front of a screen to achieve it. Some RéPPOP's members, but also field professionals, express their resistance or their interrogation about this method, which is at the opposite of their care speeches.

But, according to the coordination team members, using this type of tools can also be seen as obvious, as it's supported by the PTE principles. We can see that this device is the repository of RéPPOP's members' hopes. The RéPPOP actually defends its project with some promises MyMouv' could hold. First, it could allow for a long and close follow-up, as the device allows the professional to have a look at the child's practice at home. In this way, they could avoid breaking the link with their patients, especially thanks to the messaging service. Then, this device could also permit to adapt the care to the patient's needs, by defining personalized goals and encouraging the children with challenges; therefore customize the care. Finally, it could be a solution to improve the involvement and the autonomy of patients. As the child practices alone, at home, without the control of the professional, he must find the motivation to move. But, he also has to understand the rules of a good physical activity, to manage his effort. To help him in this process, he could follow his progression by self-assessment, with scales and questionnaires included in the application. Those features designed with the principles of therapeutic education in mind could make the implementation of the device easy in this type of care. But we will see in the second part of this article that using this tool is not that simple.

The RéPPOP supports the MyMouv' development with lots of hopes and promises, but the coordination team members are also confronted with a number of issues and difficulties in the whole health system during the designed and IT development of this tool. First, there are coordination issues between the clinical and the technical sides of the project. As we saw above, the coordination team hopes to improve the care of childhood obesity with MyMouv', by following therapeutic education principles. But these clinical concerns come into conflict with technical issues and constraints. Indeed, all the codes need to put the facts into boxes. Computer scientists need to code "reality", but care is not as simple as boxes, so it could be difficult to contain it in technical objects. For example, it is easier for the IT engineers to focus on simple quantitative data to follow the practice, as weight or size, than on more qualitative aspects, as self-esteem or the pleasure during practice. Moreover, clinicians and engineers do not speak the same language and it is not easy for one party to understand the other. As a consequence, the exchanges during MyMouv's development were more focused on the understanding of technical constraints by the coordination team, and less on the ways to introduce their health model into this tool. Then, there are ethical issues linked to health democracy. The current health model does not make a big room for patient words. The RéPPOP is trying to change that, but it is actually difficult to let the patient have a role in his care, as there is a traditional asymmetry of knowledge and power between the patient and the healer, which leads to a paternalistic relation (Pierron 2007). And especially with children, who are still dependent on their parents. Moreover, the RéPPOP has an important issue to handle, linked with health democracy, being the promoter of therapeutic education programs against bariatric surgery. Here again, there is the RéPPOP's will to base the care on prevention, first care, and education rather than on surgery and cure, which are the traditional cares at the hospital. Then, there are lots of institutional issues that can impact the health care pathway, such as the hardly compatible temporalities of the different institutions involved in this project; which are the financing foundation, the

hospital where the RéPPOP is based, and public institutions to which the RéPPOP is submitted, since this network is an association. All these institutions have different roles in the MyMouv' project, so they can influence its development. For example, the RéPPOP needs the approval of a public institution, the CNIL (Informatics and Liberties National Commission), to store data and to use them. But, the agreement to their device will take months, slow down the process, and delay the test phase of MyMouv'.

The financial means are also a big issue for the RéPPOP as all the financing for the development was a donation from an association "Hôpital Sourire". The budget was really small for the IT engineers to design an e-health tool so it did not allow the RéPPOP to create all the features they wanted. They had to renounce to several specifications, like the transformation of this application into a serious game or the connection with activity trackers. Even if both of the teams of the RéPPOP and of the IT engineers took on their own budgets (mainly working time) to help finish this tool, they had to make various sacrifices.

Therefore we can see that the coordination can be difficult in the health care pathway during the tool designing, between the institutions, but also between the different professionals.

Using MyMouv': using technology in the childhood obesity care pathway, professionals and patients' resistance

The designing phase is not the only one that was challenging; using an e-health tool can be as well. Several factors can impact the commitment of the users of MyMouv', both patients and professionals. We will see that the lack of coordination between all the actors in the conception and IT development stages leads to appropriation difficulties for the users in the test phase. The needs integration deficiency actually reveals some users resistances.

First, we emphasize the influence of the professionals' socializations and especially their conception of childhood obesity and its care. The results of our interviews show that the sport teachers using this tool the most are the professionals who have a bio-physiological conception of obesity and its care, based on the energetic scale, i.e. on physical activity and diet. Some others give more importance to the psycho-social care, which focuses on the consideration of the patients' environment and situation. Given that the MyMouv' device deals only with physical activity follow-up, some professionals with a wider concept of care can be frustrated that it does not go into the other sides of the care in depth. Moreover, commitment to the use of the device also depends on the professionals' concept of the physical activity care. In that case, we can see that the ones who use MyMouv' the most are the ones who have a performance conception of physical activity. Actually, this tool, as a smartphone application on the patient's side, shares some values of others connected health tools, like the increase of performance, the practice control with numbers and somehow a moralistic value, whereas lots of sport teachers encountered in the childhood obesity care are more interested in the patients pleasure during practice, and working on others values like team work, the increase of self-esteem, etc. Yet, all these aspects

cannot be followed by using MyMouv'. This explains why some professionals,⁴ even if they are really interested in the idea of having a close follow-up with their patients, do not commit to the use of this application.

Another challenge in incorporating this device in the health care pathway is that it comes into conflict with current professionals' practices. First, there is the matter of social status, because lots of the testers work as volunteers, half time jobs or replacements. As a consequence they have difficulties managing their schedule, especially if they do not have financial help to include the use of the device in their work. Some of the sport teachers interviewed highlight the fact that they do not have time during their practice to test MyMouv', so they have to do it during their free-time. Financial promotion is an important issue in e-health especially as understanding and integrating these new tools is time-consuming, and they often do not replace old tools, but become an additional task (Méadel, Akrich 2010). Moreover, in health institutions each act is coded and equals a financial value in the financial software, but e-health is not equivalent to any code (CATEL 2014). So the professionals cannot add value to their work by using this kind of tool.

The type of follow-up model used by sport teachers for the care is a third factor that influences the commitment in the use of this tool. The sport teachers who follow patients in therapeutic education program see them only for two consecutive days; since they do not handle the long term follow-up, this tool seems useless to them. There are also some testers who work in aftercare and rehabilitation center care, in this case, they see the children once or twice a day, for two weeks up to two months. But then they do not do the long term follow-up either, so this tool can be seen as a burden, as they have to manage the follow-up of the children who left the center and who are cared by other professionals outside. The sport teachers highlight the fact that it could become an enormous work load for them. Finally, the sport teachers who seem to be the more concerned by this device are the ones who lead adapted physical activities workshops. These sport teachers take care of their patients during their lessons, which take place once or twice a week throughout school year. With MyMouv', they can follow the practice between sessions and improve the patients' motivation, especially during holidays for example. They are the ones who commit the most easily to use MyMouv'. With this focus, we understand that it seems essential to define when and how the sport teachers must use the device. The coordination team has to define how it can be included in the health care pathway, in which step of the care. It is supposed to be used in the therapeutic education model but no instruction was given about the type of professionals who can use it (trained to PTE or not) or about the type of care (PTE programs only, or during all the care's steps).

Finally, all these factors are influenced by the professionals' closeness with the RéPPOP coordination team. Indeed, the sport teachers who commit the most to using MyMouv' are the ones who work the most with the members of the coordination team, who share other projects with them. In that case, the testers also share some goals and values, and better understand the issues surrounding the development

4 Three out of four professionals who have a bio-physiological conception tested the device, but only one out of three professionals who have a psycho-social conception did.

and the use of MyMouv'. These exchanges raise awareness among sport teachers and increase their commitment. We can see with these results that grabbing the interest of professionals is easier than federating them or involving them in the real test phase. But we can also highlight the importance of integrating the sport teachers into the development of this kind of tools, as the closeness with the team and the project is a factor influencing strongly their commitment. We can see that maximalist coordination modes, discussion with the users and their integration in projects, can improve this process.

Using MyMouv' can also be challenging according to the patients' situation. Epidemiology researches show that in obesity, and childhood obesity, patients are from precarious social classes, with lower incomes and lower school levels (Charles 2010). According to the sport teachers interviewed, several difficulties ensue. First, the children do not always have the correct equipment to use this tool: a powerful smartphone with an Internet access to download and use the application. They can also be discouraged by all the exercises descriptions written and detailed in the device, because they require good school skills such as reading comprehension.

So even if the designers thought that using a smartphone application was a way to involve lots of kids and teenagers, based on the assumption that they would be familiar with this technology, we can see that they did not take into consideration the socio-economic characteristics of this population.

Testing and using MyMouv' is also a source of disillusion. Professionals and patients had lots of expectations regarding the device, but as it is in testing stage, it is subject to technical malfunctions. Plenty of bugs can discourage the users, especially synchronization issues, passwords glitches, or incompatibilities with some smartphones. Moreover, patients expected to use this application in a way close to those they already use and know; but they were disappointed when they discovered it because of some missing functionalities, for example of the lack of social interaction as there is no discussion group or connection with other users, or the absence of notifications. As a result, they have to make a willing step to use it, which requires a lot of motivation. In the same way, MyMouv' is not playful, and is not built as a game, which calls for more patients' motivation.

In this case, we also understand the necessity of integrating the users, both patients and professionals, in the designing of this kind of tool, to pinpoint better their needs, and so to build an application which fits the users' expectations and situations.

Conclusion: a lack a coordination in the development which leads to a lower appropriation of MyMouv' and a lack of integration into the health care model

We saw with this study that designing and using an e-health tool is not self-evident. Several factors must be taken into account during the development of a specific tool like MyMouv'. Lots of constraints can appear during the development process and can complicate the users' commitment in its usage. We saw that the minimalist coordination between all the actors leads to the creation of a tool which does not fit the users' practices. The lack of users (both professionals and patients) integration in the design process actually leads to misunderstandings and then disappointments.

Moreover, we saw the important influence of health model. First, in the design of this tool, as it is built on the therapeutic education model principles. In this way, it requires some specific competences: on one hand, from the coordination team, as they have to think the tool through all these principles; on the other hand, from the testers, who have to master this kind of care, so they can use MyMouv' in the way thought by the designers. Then, the health model is also essential in the using phase, as we saw that some professionals cannot commit to it as their care model is distant from the MyMouv' model. It is paramount in that case to think about the role of e-health tools in the health care pathway.

On the whole, in a therapeutic education model, introducing an e-health tool appears really challenging, and must be considered as such. It brings lots of questions: what place do the RéPPOP want to give to e-health? How can it do it serve PTE? Do we want to integrate this tool and e-health in the health care pathway, or is it just a tool at the service of the professional, in defined situations?

To understand better this process, we are pursuing our research on this tool, but also others e-health tools designed by the RéPPOP so we can study the multiple issues undermining the development of these devices. We would like to clarify the structure of the social and technical network, to understand the links between all the actors and their roles at the different stages of development and how it can impact at the same time the development, the final tool and its use.

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Abstract

Our study focuses on MyMouv' device, a follow-up tool of the physical activity practice for obese children and teenagers, conceived by the RéPPOP (Prevention and Care of Paediatric Obesity Network) in Midi-Pyrénées, France. It aims at optimising the children health care pathway in physical activity and for supporting motivation to move. This device questions in a frontal way the impact of e-health on the health care pathway, especially with children. Indeed, such a tool leads to some issues about its place in the care, particularly about ethical, social and clinical topics linked with its use. We question the effective realities of this display but also the actual impact of 'non-humans' on the health care pathway and logics with the increasing development of e-health devices. We show that using this e-health tool in the patient health care pathway is not self-evident, by studying its development and test stages.

Key words: e-health; pediatric obesity; coordination; appropriation; application; health care pathway

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