

Treatment and monitoring remain the purview of the doctor: Health literacy of people struggling with insufficiently controlled type 2 diabetes. A longitudinal qualitative study

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Research article

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Abstract

Background

Assessing complex health literacy needs is a key element to improve management of diabetes in vulnerable people. This study aimed to analyse health literacy and practices in insufficiently controlled type 2 diabetes.

Methods

Data are issued from the qualitative ERMIES-ethnosocio study nested in the ERMIES randomized controlled trial testing a 2 years structured care in type 2 diabetes. A total of 42 participants were seen at the beginning and after the completion of the trial. Interviews explored experiences and views on daily management of diabetes. Health literacy was assessed via the multidimensional Health Literacy Questionnaire.

Results

Eight themes grouped in 3 main poles could be individualized: health knowledge, disease management, expertise and social support. Participants exhibited a primarily one-way relationship to treatment and monitoring, leaving the health care providers (HCP) the initiatives. In contrast, relation to food practices and exercise were more interactive. After 2 years participants tended to engage a more interactive relation to treatment. Having sufficient, appraising, and feeling able to find good health information were at stake while social support for health and relation to HCP and services were important determinants for managing health.

Conclusion

This longitudinal qualitative study shows the inter-individual et intra-individual variations of health literacy related to disease management, with the importance of the relation type to HCP, as well as social context with complex and evolving interactions. Decision-making as a shared social task beside the resources for engaging with health services are key considerations in the co-design of relevant interventions in type 2 diabetes.

Background

Type 2 diabetes mellitus is a long-lasting silent disease subject to threatening complications [1]. Long term management and prevention of complications is challenging [2]. Patients often struggle with the everyday constraints, treatment adherence, and follow-up monitoring [3–5]. Diabetes management includes medical care from physicians and healthcare teams, self-management by the individual with

diabetes [6, 7], and social support [8, 9]. Beside medical diagnostic and therapeutic measures, self-management education and support has been shown crucial in helping persons with diabetes manage the disease while maintaining quality of life [10, 11]. France, with a high level of health insurance coverage, has been confronted to a health system primarily dedicated to acute care, struggling to establish a real chronic care coordination [12]. In spite of a slight improvement in the quality of care and follow-up between 2001 and 2007, the French ENTRED study has shown that only 17% of type 2 diabetes patients participated in self-management education, mainly in hospital setting, and/or conducted by their doctors [13]. Only 2% of treated diabetic patients received all of the recommended monitoring regular exams and follow-up and treatment of people with type 2 diabetes is mainly managed by primary care physicians [14]. In contrast to a self-efficacy rated as high by many patients regarding nutrition, exercise, treatment management and self-monitoring of blood glucose [13], the level of medication adherence is quite low [15], and the complications of diabetes remain frequent and severe, with increasing social and regional disparities [16]. Reunion island, a French overseas department, as an example, is characterized by the contrast between the best quality of follow-up recommendations, and the highest prevalence of complications [16, 17].

Health literacy refers to the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health [18]. Health literacy involves the ability of individuals to implement health-relevant practices, understand their meaning, and adapt these practices considering the strengths and limitations of environments and contexts in which they are actualized [19]. Health literacy is the result of the balance between the individual skills and the relationships with health professionals, services, and system. Health literacy has been linked to numerous health indicators and outcomes [20] and is a key component of health perceptions and practices [21–23]. In diabetes, health literacy has been mainly assessed through functional tests of reading ability, understanding, and/or numeracy and has been linked to glycaemic control, hypoglycaemia, retinopathy, treatment understanding and dosage adjustment, disease knowledge and patient-provider communication [24]. Recent tools to assess the complexity of the health literacy components have been developed, which encompass the constructs at stake as regard to the access and appropriation of health information and services [25]. Using the Health literacy Questionnaire, studies have shown difficulties in actively managing health, health information finding, understanding and appraisal, as well as ability to engage with health care providers [26, 27].

The present study aimed at analysing the relationships between health literacy and health practices at stake in diabetes management, in the context of a structured self-management intervention, using qualitative longitudinal interviews and assessment of health literacy via the HLQ.

Methods

Study design and population

The present study was part of the mixed ERMIES randomized controlled trial. The main objective of ERMIES was to evaluate the efficacy on HbA1c progression of a structured self-management education intervention maintained over 2 years and was conducted in under-controlled type 2 diabetes (HbA1c > 7.5%). Out of 4 centres (diabetology outpatient settings of the 4 hospitals of the island of Reunion), 100 people were included between October 2011 and November 2014 [28, 29]. All participants underwent a 3-month self-management education course composed of 3–6 sessions, and then were followed quarterly (medical and biological check-up) for 2 years in the outpatient hospital setting. A randomized intervention group was invited every 4 months to attend a structured group session.

The nested qualitative study included 44 subjects. Interviews were conducted in 2012 with consecutive participants included in ERMIES who agreed to participate in the qualitative study. A second round of interviews took place at the completion of the study in 2015 for 42 out of the 44. When included, all participants were informed of the conditions of the research. They signed a written consent for conducting a qualitative survey by interviews that would be conducted at home. When making an appointment (before each interview) new information with oral agreement was given.

The ERMIES study received the agreement of the CPP Sud Ouest Outremer III 20/01/2011, amendment of 10/05/2011 for the nested longitudinal qualitative study.

Qualitative study

First round of interviews

Research assistants conducted the interviews, which lasted one hour each on average, at the participants' homes. Interviews focused on diabetes, cardiovascular risk, self-monitoring, access to information, relationships to education and learning, participant positioning, decision-making, environment and support. The participants were invited to describe the onset and development of diabetes, as well as their behaviour in hospital, domestic and occupational settings, and in socio-cultural contexts such as family events. Specific topics included were the history and progression of the illness, knowledge acquired and sources, food practices, physical activity, monitoring and treatment of diabetes, and the participants' perceptions of the health professionals and services. Each interview was recorded and then fully transcribed by the research assistants in the language chosen by the respondent. Transcripts of interviews held in Creole were subsequently translated into French.

The 44 interviews were studied using content analysis of recurrent themes [30]. Categories and signifiers were developed using the constant comparison method [31]. The themes which emerged were tested and modified during additional cycles of data collection. The saturation of data, with a wealth of social configurations and relations to health, hospital and home environment, could be obtained despite the practical constraints of the recruitment of participants immediately after the inclusion in the ERMIES study. The work was done on the N-Vivo 10 QSR International qualitative analysis software, which allowed the qualitative data collected to be processed and several themes constituting the management

of diabetes in the ordinary context to be determined. For each of these themes, we identified three types of relationships in reference to the categories of health literacy established by Don Nutbeam [32] :

- A "functional relationship to ...", or an instrumental relationship to (diet, physical activity ...), tasks being exercised without a critical look in everyday situations.
- An "interactive relation to ..." that engages cognitive and social skills used to participate actively in everyday activities, infer the meaning of different forms of communication and apply the new information to changing circumstances.
- A "critical relation to ..." that mobilizes more sophisticated cognitive and social skills, applied to a critical analysis of information and their use to exercise greater control over the events of life.

The first names used here for the quotations are fictitious.

Second Round of Interviews

Based on the analysis of the initial interviews, we created a qualitative data collection grid that was proposed in 2015 for 42 participants (2 out of the 44 dropped out). This grid, covering 8 authenticated themes and the 3 levels of "relations to" was completed both by the interviewee and the interviewer. All interviews and exchanges around the grid were recorded and transcribed in full, which, in case of distances in the responses, made it possible to listen to each speech again in the presence of another researcher.

The coding and analysis were subjected to a triangulation process carried out by three members of the research team (DB, JC, MBD). The data from the 44 interviews and the second round's grids of interviews of behaviour at home were crossed-referenced in two ways: for each participant (which made it possible to produce case studies of participants), but also by specific themes (food, physical activity etc.) taking the whole of the corpus into account. This work made it possible to show intra and inter-individual variations relating to the talks and practices in relation to the disease and its management, the world of healthcare, the social and familial environment, and involvement in conduct for prevention and health (food, physical activity). The analyses were concentrated on the present of the individual, particularly in relation to health knowledge, health practices, and health services.

Health Literacy Questionnaire

Health literacy was explored using the Health Literacy Questionnaire (HLQ), a multidimensional questionnaire with robust psychometric properties [25]. Composed of 44 items, the questionnaire explores 9 dimensions (Table 1). The original English questionnaire had been translated into French, following a rigorous procedure and exhibit robust psychometric properties [33]. Questionnaires were self-administered during the second round in 2015, before interviews, for 39 participants among 42.

Table 1
Health Literacy Questionnaire scales.

HLQ scales	1st part of the questionnaire	
Response options from 1 -strongly disagree- to 4 -strongly agree-		
1	Feeling understood and supported by healthcare professionals	4 items
2	Having sufficient information to manage my health	4 items
3	Actively managing my health	5 items
4	Social support for health	5 items
5	Appraisal of health information	5 items
HLQ scales	2nd part of the questionnaire	
Response options from 1-cannot do or always difficult- to 5 -always easy-		
6	Ability to actively engage with healthcare professionals	5 items
7	Navigating the healthcare system	6 items
8	Ability to find good health information	5 items
9	Understand health information enough to know what to do	5 items

Results

Socio-demographic and clinical characteristics of participants are described in Table 2. Most aged 50–79 yrs, were unemployed ($n = 12$) or retired ($n = 19$), with low income. Nine participants did not complete high school and 10 displayed difficulties in reading and writing.

Table 2
Socio-demographics and clinical characteristics of the sample (n = 44)

Sexe	F/M	31/13
Age (years)	[30–49]	9
	[50–59]	12
	[60–69]	12
	[70–79]	11
Household composition	Live alone	13
	Live alone, with children	4
Education level	Primary school or less	9
	Middle school	24
	High school	6
	University Undergraduate	5
Occupational status	Full- or part-time employment	13
	Unemployed	12
	Retired	19
Income)	Less than 1200 €	29
	1,200–1,999 €	7
	2,000–3,999 €	7
	≥ 4,000 €	1
Literacy	Difficulties in reading/writing	10
Diabetes, known duration	< 9 yrs	11
	10–19 yrs	19
	≥ 20 yrs	14
HbA1c at inclusion	7.5–7.9%	8
	8–8.9%	20
	9.0–11.9%	16
Diabetes treatment at inclusion	Oral agents (± GLP1 agonists)	21
	Insulin (± oral ± GLP1 agonists)	23

Sexe	F/M	31/13
Self-monitoring of blood glucose	Once a day, fasting 2–3 times a day, before meals Before and after meals	15 15 14
Known complications	Renal Heart Eye Feet Arteries None	18 10 2 5 9 14

Figure 1 displays the repartition of scores for each scale of the Health Literacy Questionnaire for the 39 participants who filled in the questionnaire. Overall, the greatest difficulties were in having, finding, using or appraising health information (Fig. 2): 23 expressed difficulties in ability to find good health information (HLQ8), and 14 in understanding well enough health information to know what to do (HLQ9); 12 disagreed or strongly disagreed as ‘having sufficient information to manage my health’ (HLQ2), and 17 in appraising health information (HLQ5). On the contrary, only 6 disagreed or strongly disagreed on Feeling understood and supported by health care providers (HLQ1), when 9 expressed difficulties in the Ability to actively engage with health care providers (HLQ6), and 13 in Navigating the health care system (HLQ7). Overall, they were a majority agreeing ($n = 28$) or strongly agreeing ($n = 5$) in ‘Actively managing my health’(HLQ3), or in having social support for health (HLQ4; agree: 17; strongly agree: 6).

First round interviews

Regardless of their socio-demographic profile, all participants stated they acted in the perspective of better health and avoidance of complications related to their disease. Disease management on a daily basis was exerted in diverse forms and contexts: at home, with the family, in the health and medical context or setting, during leisure time, or in the socio-professional sphere. A set of 8 themes could be individualized from the coding of interviews that constituted the ordinary management of the chronic disease. These 8 themes are grouped into 3 poles interacting through a complex dynamic (Table 3).

Table 3
The 3 main poles and 8 themes of disease management issues.

Poles	Themes
Health knowledge	Knowledge base
	Access to knowledge
Management of the disease	Food
	Exercise
	Treatment
Expertise, support and social network	Monitoring
	Relationships with professionals
	Health and social support

The consistency of the individual work through these 8 themes, its continuity and its inscription in the different relations (functional, interactive or critical) were constitutive at diverse degrees for participants of an optimized health and disease management (Fig. 2).

Health knowledge and access to knowledge

Relationship to knowledge and to knowledge access was primarily functional (for 29 out of 44 participants at the inclusion in the study).

'Diabetes is too much sugar in the blood' (Sylvain, 46 years old, craftsman).

'I try to listen (to the radio or TV), I try to understand, but it goes into my head but I don't understand' (Irène, 72 year, retreated)

For some participants relationship to knowledge is more interactive ($n = 11$): participants are able to make connections between at least two components, such as the links between diabetes and a balanced diet or regular physical activity. As regard to knowledge access, 13 were interactive

'...Sometimes, if my daughter arrives with her computer, she searches, I ask, and then [...] documents are sent to me all the time, so I read, there are testimonies, there are drugs, how to do it, how not to do it. So I'm following all this very closely' (Constance, 64 yrs, retreated).

At the critical level, a few participants ($n = 4$) refer to a complex system, in which interactions between the different components contribute to the evolution of the disease and its complications:

'Diabetes is a silent disease that attacks all vital organs such as the heart and kidneys. It can happen to the point of cutting off limbs. We know that it is a very serious disease' (Sébastien, 48, employee).

Only 2 participants appear to have a critical relationship to knowledge access

'Diabetes, in terms of price, drugs, it's linked to research, to laboratories that also put what they want, and then there are crazy people who can write anything. So on this side, there is a lack of control over what is shown on the Internet. (...) It's a gold mine, but you have to know if it's gold, real or synthetic.' (Damien, 73 yrs, retreated)

The 'ordinary' management of disease

Food and exercise

In 2012 at the study initiation most participants (24/44) exhibited a primarily functional relationship to diet.

'To eat, I eat about as the hospital tells us to do and what it gives us'. Delphine, 50 yrs, unemployed.

However, one third (14/44) were more interactive

'I even get to correct something when I make a mistake during a meal the next time. I know how to follow my diet and how to promote it in relation to my diabetes.' Ludivine, 76 yrs, retreated.

or even critical (4/44)

'it's in the way you cook things... for example, eat a cod cari, well, you have to put oil in it, otherwise how else? well, that's exceptional, ... we have a fish cari, if for example I do toothfish, I put almost no oil because toothfish is already a fish that is fat, even if it is good fat'. Blandine, 57 yrs, account manager.

Similarly, the relationship to exercise was mainly functional (29/44)

'I go to the health network with people for sports but that's fine they do about 15 days but then there's nobody left, we can't do it alone, we don't really know how to do it, we're afraid to fall, be careful in the way... we are motivated to go because there is someone who will show us what to do, what not to do, explain: okay do two or three laps, you run slowly... but ourselves..., I can't do it alone, I can't, that's it'. Irène, 69 yrs, retreated.

Treatment and monitoring

The relationship to treatment and monitoring was functional for most participants (36 and 39 respectively on a total of 44).

'I take all the medicines as required [...] I have an appointment with doctor X he will see if I need to add a medicine' (Beatrice 64 yrs, occasional saleswoman)

You have to trust the treatment, because the doctor prescribed this for us...we've been told that this drug is good for us...it's up to us to follow the treatment we've been given....' (Charles, 56 yrs, Gardien)

'So the doctor can check the blood sugar level: it's how high and all that, right now it's high, it was 7 comma something, and now I'm at 8 comma so it's not good. No if it's not good I just go in the same way because I don't eat nor so much, like at lunchtime I only eat a piece of bread for lunch, nothing else'.
(Brigitte, 62 yrs, retreated)

A few participants were more interactive, especially regarding self-monitoring:

'On Tuesday, I made 1 hour of Taiichi, my test was 1.30 in the morning, 2.04 after breakfast, 1.31 at noon. I made Taiichi, 1.96 after lunch, so the benefit of Taiichi continues. I was at 1.06 in the evening.[...] Wednesday I was at 1.59 and after breakfast I was at 3.02 but I know why: I ate a banana and then at noon I went shopping from 10.30 to 12.00 but I dropped my car as far away as possible so that I could walk, I don't go in front of the shop, I put my car over there. My blood glucose was 0.85 at noon, well when I ate I was at 2.09 grams afterwards and in the evening I was at 2.99 grams but in the afternoon I didn't just lie there in the armchair, I ironed clothes, I emptied my cupboard, I tidied up, these are little things, but it makes me move, that's it. And today, the same, I was at 1.20 this morning, I was at 2.50 at 9.30, I did one hour of gym, at noon, at 12.27 it was 0.99'. (Ludivine, 73 yrs, retreated)

Only one participant exhibited critical relationship to treatment and monitoring of the disease:

'I have my insulin injections, three injections a day and then checks with the measuring device [...] As the occasion arises, I'll do other checks during the day, sometimes just in the evening, we'll try to see, well is it hypoglycemia, things like that, we're trying to define [...] Well at one point, I had stopped [the bike] because it was too hot and so there, as I didn't change my treatment, obviously the treatment was too strong and so I got hypoglycemia...'. (Guillaume, 66 yrs, retreated, artist)

Expertise, support and social network

The relationships with health care providers was functional for 26/44.

'There's the nurse who comes to prepare my medicine. Before that, I used to take, I had all the drugs, but I just didn't understand, because I can't read very well, so I used to take the drugs in a mess, any way ... and now the nurse comes, she prepares everything in the morning.' (Tatiana, 70 yrs, unemployed)

but more often interactive (16/44) than for treatment or follow-up.

' I'm more used to Dr. X, he knows my problems so I prefer to see him personally, he helps me a lot morally. Sometimes, when you see 3 or 4 grams like that, I can't stand it very, very badly. So I'm closer to Dr. X than the others. And then there's Nurse Y who explains very well, who's a good nurse, frankly I have nothing to say, well maybe they serve to support me too, morally and medically, that's it' (Constance, 51 yrs, retreated)

All of those who displayed functional relationship to HCP were functional too for treatment (except 1 interactive) and disease follow-up. Interestingly, the interactive nature of the relation to HCP was not associated with interaction in treatment for 11 out of 16 or in monitoring (14/16).

Social support

In most cases, participants did not feel isolated in the management of their illness: 26 out of 44 participants receive real family or friends support, which was expressed as much in the form of solidarity as in the family sharing. This relational frame crystallizes around eating practices '*Everyone at home eats the same since I became diabetic*' (Adeline, 73, retired), physical activity '*Sometimes when you decide, it's either her or me, you walk a little bit*' (Sylvain, 47, artisan) or in understanding the disease: '*It's true that my husband, working in the hospital, it helped me a lot*' (Blandine, 60, employee). This support differs according to the relative, as Clarisse (55 years old, no professional activity) testifies: '*Yes, maybe not with my partner but my children, and then there is my family nearby, my sisters, my brothers, my parents, so no worries*'. In some cases, the person concerned with diabetes prefers to spare his or her family by taking charge of the management of the disease himself or herself. '*For me, it is not a handicap, diabetes is there, we manage and that's it. (...). I never talk about it (diabetes), it's my case*' (Sabine, 69, retired).

Functional, but also interactive social support was associated with functional follow-up (16/17 and 23/26) and functional treatment (15/17 and 21/26), but not always with functional relationship to food (11/17 and 15/16) or exercise (11/17 and 17/26).

Second round of interviews

The interviews conducted twice for 42 participants at the beginning and end of the ERMIES study highlighted changes over time in the variables that are constitutive of the relationship to disease management, but in a differentiated way according to individuals and backgrounds.

As a whole, health knowledge and access to knowledge exhibited a shift towards a more interactive and critical relationship among participants, slightly more in the intervention group than in controls. Most important evolution was seen on the management aspects, particularly regarding food, with lot of participant moving functional to interactive (Fig. 3). With regard to physical activity, the many passages from interactive to critical showed that participants have understood the benefits of physical activity and were better able to integrate it into their practices. For these 2 variables (food and exercise), the evolution was observed in both intervention and control group participants. The evolution towards interactive or even critical was also objective for disease follow-up and monitoring, but here more frankly among the participants of the ERMIES intervention group. However, the relationship to treatment remained mostly at a very functional level (28 out of 42), whatever the randomization group, and few participants modulate and adjust treatment by themselves. There was a clear evolution of many participants towards a more interactive relationship with HCP. Social support was less functional too.

Discussion

In diabetes, both patients and HCP are confronted in real world to the management of the disease on a daily basis and on the long term [4, 34, 35]. Health literacy is a potential determinant in attaining lifestyle behaviour, medication adherence, and adequate monitoring of the disease [36, 37]. This qualitative study,

in which 86 interviews at home and in outpatient settings were made to 44 people at the initiation and after the completion of a structured 2-year follow-up, has shown the multidimensional nature of health literacy in relation to disease management. The 8 themes individualized could be grouped in 3 poles: the ordinary management of the disease, the relation to disease knowledge, and support (social and expertise). The ordinary management of diabetes was constituted by distinct postures for lifestyle behaviours on one side, and for medical aspects on the other: participants exhibited predominantly a more active (interactive or critical) relationship to diet and exercise than to treatment and monitoring. This was even more sizeable after 3 years, with most participants remaining mainly functional for treatment and monitoring, while being interactive or even critical on exercise and diet. Social support, and relation type with HCP were important elements associated with a more interactive or critical health literacy as regard to disease management. These results were strengthened by the health literacy profiles largely exhibiting higher scores on the HLQ scales related to health care providers and services (Feeling understood and supported by health care providers, Ability to actively engage with health care providers, Navigating the health care system), and at the opposite lower scores on the HLQ scales related to health information (having, finding, using or appraising).

In this population of participants struggling with insufficiently controlled type 2 diabetes, our results highlight the predominant perceptions and attitude of patients regarding treatment and monitoring remaining under the expertise of HCP. O'Connor et al [38] found that patients who did not improve glucose control were more positive about their care providers, unquestioning acceptance of the doctor's role and treatment. At the opposite, a less passive approach to HCP, as well as a strategic non-compliance with medication have been described as key elements in succeeding in diabetes management and well-being [39]. Timely information and support from HCP, adapted to the actual individual constraints allow sustainable efforts for self-management [40].

A certain level of knowledge about diabetes is needed in order to make adjustments to the treatment. Knowledge gained by experience is then more valued than the doctor's generalised scientific knowledge [39]. Friis et al [41] reported the high treatment burden in patients with chronic multimorbidity and difficulties in understanding health information. This is in line with the apparent contrast found in the present study between the level of sense of being supported by HCP and struggling with diabetes control and handling of own useful and relevant health information. For many participants, letting the caregivers take the reins of conducting and adapting medication, as well as providing long-term monitoring, made it possible for them to get involved in the challenging daily tasks of making the required nutritional and exercise changes. Studies in UK revealed also the importance of HCP attitudes regarding blood glucose readings for the continuing and relevant self-monitoring [42]. Moreover, patients lacked understanding of what to do faced to blood glucose results, as what could be noticed too in the present study.

Social support appeared here to be frequently associated with active management of disease. Maintaining self-management is a hard daily task, demanding individual investment as well as social, familial, not just taking regularly medications and coping with lifestyle [4, 43]. On the basis of individual dispositions issuing from time and experience, the power of the everyday context surrounding key

practices to control and overcome illness have to be considered [3, 40]. Low personal resources, e.g. regarding the appropriation of health information, together with burdensome family and social situations may explain difficulties in engagement with self-management [40].

Strengths and limitations

The main strength of this study is its longitudinal design, with interviews repeated after the completion of a structured managed care. Interviews were conducted at home, taking into account particular features and social contexts, in a sample of participants who displayed actual difficulties in managing insufficiently controlled diabetes, and mostly in a long-standing duration of diabetes.

Nevertheless, this study has some limitations. Firstly, the context of the study must be acknowledged, during a comparative intervention trial with structured intensive managed care under the coordination of specialized secondary outpatient centres, and in Reunion island, a French outmost territory, with deeper contrasted social disparities compared to metropolitan France. Hence any extrapolation must be done with caution, even if, conversely, this context makes it possible to better grasp elements specific to disadvantaged populations. First round interviews were held in the weeks after the inclusion in the trial. This may have influenced the discourse on practices and relationships with caregivers, even though before the initiation of the initial education course. The second round of interviews took place after 2 to 3 years, following a structured managed care, so that the attitudes and relationships to HCP, treatment issues, and monitoring could have been influenced. Nevertheless, the results underline furthermore the needs of participants for other types of support from HCP and services, as exhibited by the combination of the HLQ profiles obtained together with the second round interviews: education and support have to work on the actual contextual factors that make sense in decision making and sharing and in the appropriation of relevant health practices on an everyday basis. More specifically, the transition from a passive attitude towards monitoring and the elements allowing for the relevant adaptation of treatment and health practices in accordance with the evolution should be the subject of a process of appropriation in which the particular contexts should be apparent.

Conclusions

This longitudinal qualitative study, nested in a long-term comparative intervention trial of structured managed care in vulnerable participants struggling with type 2 diabetes and low health literacy, shows that decision making and handling of treatment and disease monitoring remains primarily the purview of HCP. Although other studies had already provided data showing the role given to health care professionals by chronically ill people in difficulty, the results show the ability to engage in lifestyle behaviours while letting the reins of treatment and disease monitoring awareness to the doctor. The multidimensional nature of disease management and of health literacy, both embedded in social configurations, has to be acknowledged. Decision-making as a shared social task beside the resources

for engaging with HCP and services are key considerations in the co-design of appropriate interventions for uncontrolled type 2 diabetes.

Abbreviations

HCP

health care providers

HLQ

Health Literacy Questionnaire

Declarations

Ethics approval and consent to participate

The ERMIES study received the agreement of the CPP Sud Ouest Outremer III 20/01/2011, amendment of 10/05/2011 for the nested longitudinal qualitative study. All participants were informed of the conditions of the research. They signed a written consent for conducting a qualitative survey by interviews that would be conducted at home. When making an appointment (before each interview) new information with oral agreement was given.

Consent for publication

Not applicable

Availability of data and material

Not applicable. The nested qualitative part of the ERMIES study did not use any quantitative dataset. Qualitative data constituted by full transcript of interviews are subjects to confidentiality and highly sensible. If needed, and on reasonable request, it is possible to obtain an anonymous dataset.

Competing interests

The authors declare that they have no competing interests.

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study is the Regional Teaching Hospital of La Réunion, France. The funders bodies had no role in the design of the study and collection, analysis, interpretation of data and in writing the manuscript.

Authors' contributions

Conception and design of the nested qualitative study were performed by MBD, DB and XD. Material preparation and data collection were performed by MBD, DB and JCS. Data analysis by DB, MBD, and JCS. The first draft of the manuscript was written by XD. MBD was a major contributor in writing the manuscript. Members of the ERMIES Study Group were co-investigators and invested in the design and conduct of the ERMIES RCT study. All authors read and approved the manuscript.

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Figures

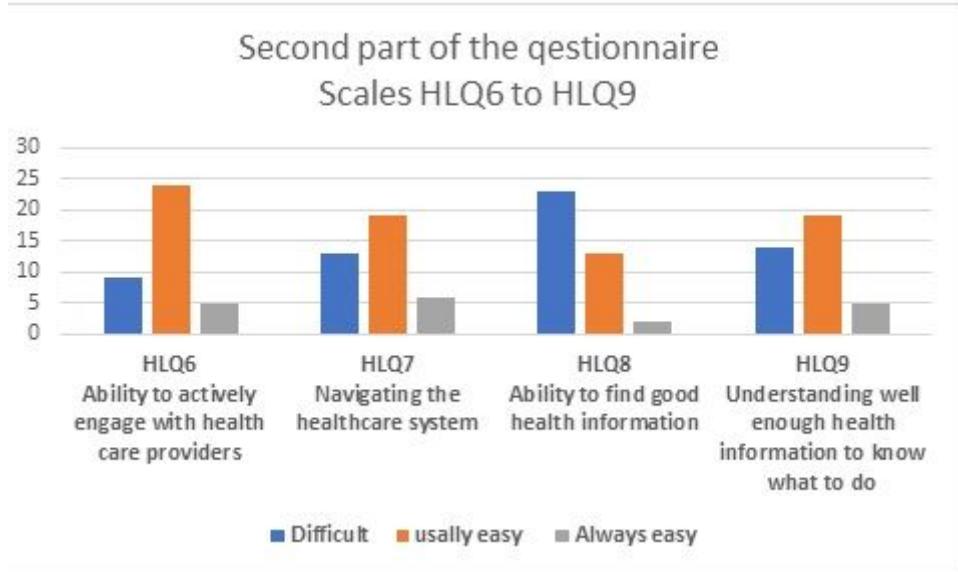
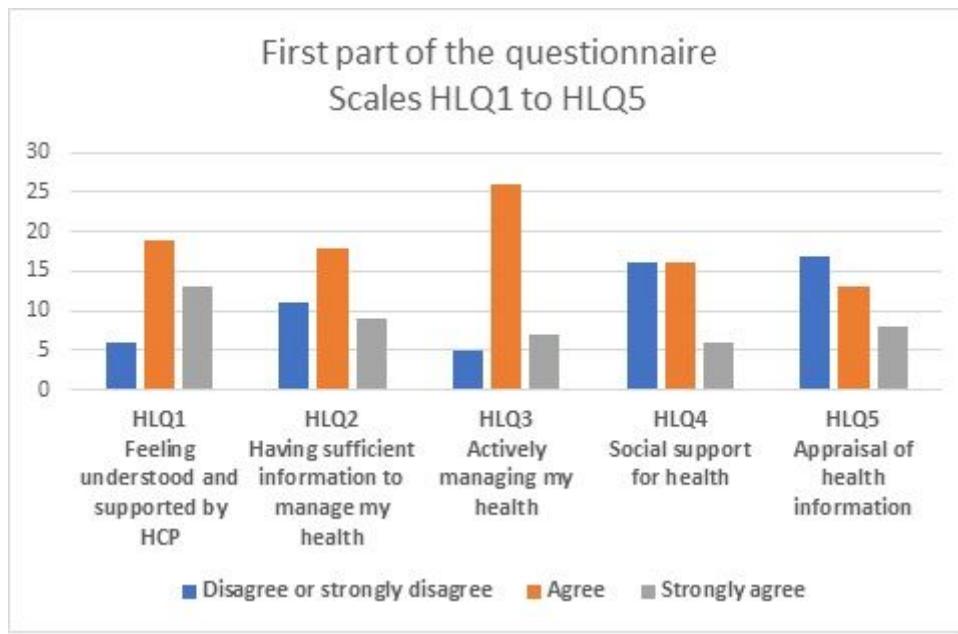


Figure 1

Repartition of individual health literacy profiles among the 9 scales of the Health Literacy Questionnaire. Ermies-ethnosocio study, n=39. Cut-off scores were: - for scales (1-5) of the 1st part of the HLQ: <3 Disagree or strongly disagree; 3-3.5 Agree; ≥3.5 Strongly agree - for scales (6-9) of the 2nd part of the HLQ: <3.5 Difficult; 3.5-4.5 Usually easy; ≥4.5 Always easy.

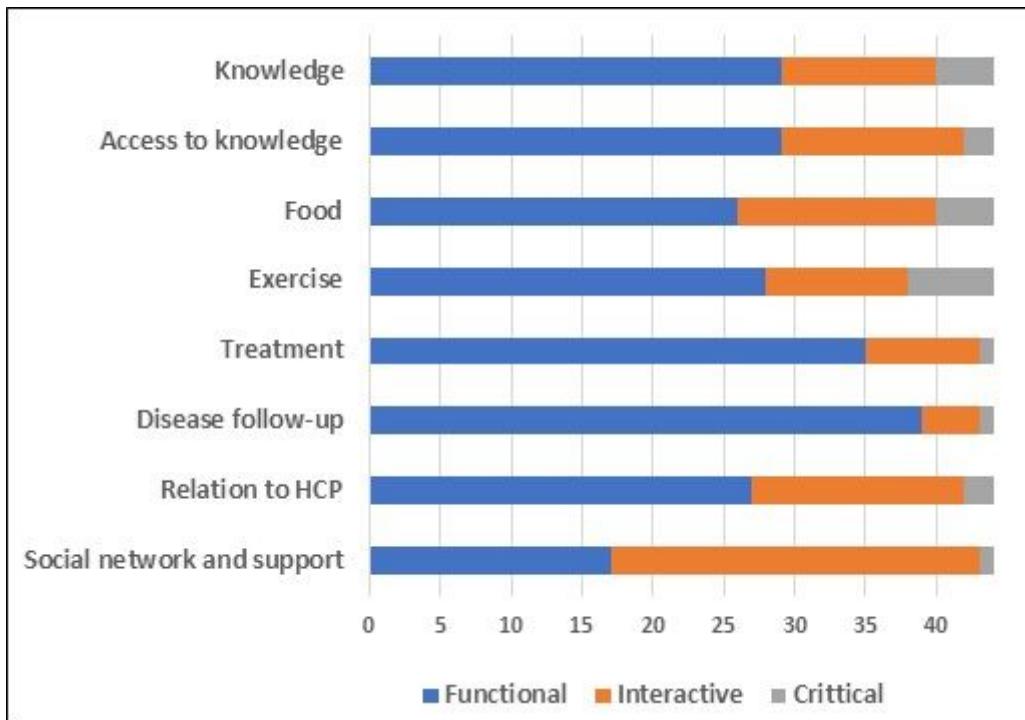


Figure 2

Disease management. Functional, interactive and critical relationships to the 8 themes. First round interviews, n=44

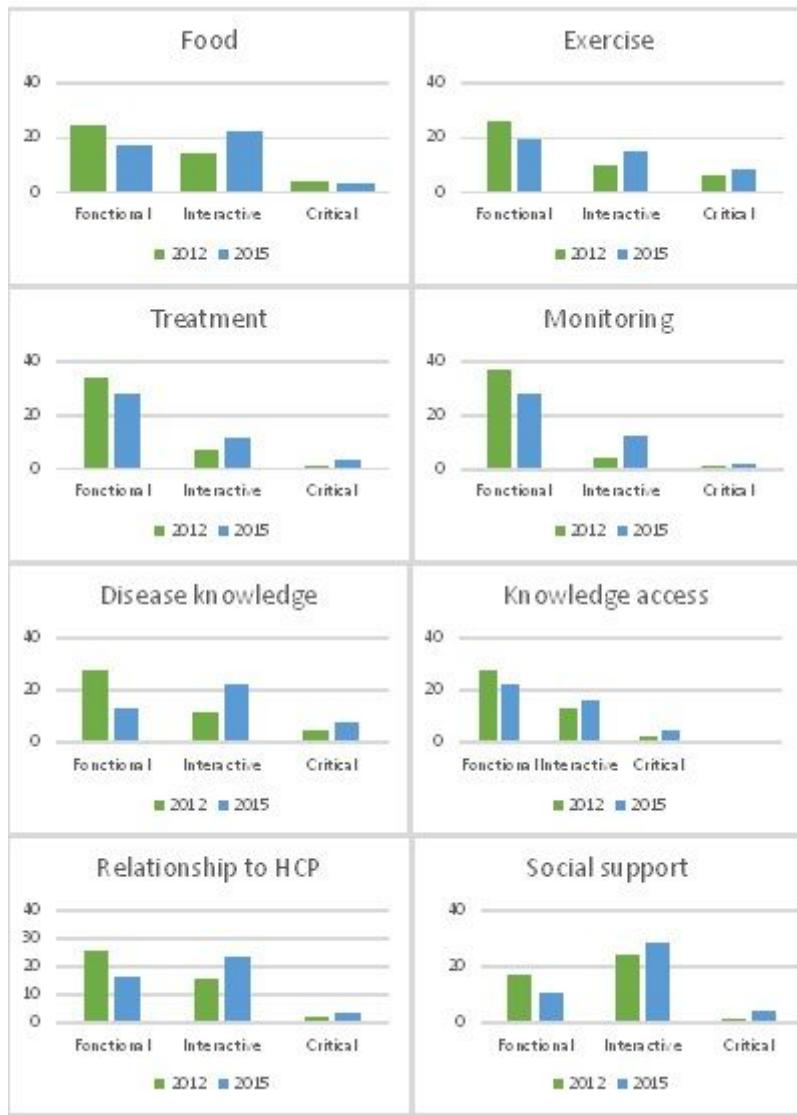


Figure 3

Functional, interactive, and critical relationships to the 8 themes of disease management: Progress from 2012 (1st round interviews) to 2015 (2nd round interviews). Ermies ethno-socio study, n=42.