BMJ Open

Health literacy in context: struggling to self-manage diabetes – a longitudinal qualitative study

Xavier Debussche ![ORCID] ,[1,2] Maryvette Balcou-Debussche,[3] Delphine Ballet,[3] Jessica Caroupin-Soupoutevin[3]

![Check for updates]

¹Centre Expert Plaies Chroniques, Centre Hospitalier Max Querrien, Paimpol, France
²Centre d'Investigations Cliniques CIC1410, Institut National de la Santé et de la Recherche Médicale, Saint-Pierre Réunion, France
³ICARE EA7389 Austral Cooperative Institute for Research in Education, Reunion University, Saint-Denis, Réunion

Correspondence to
Dr Xavier Debussche;
xavier.debussche@inserm.fr

ABSTRACT

Objectives Considering health literacy needs is a key component of health services responsiveness to diabetes self-management among vulnerable individuals. The purpose of this qualitative study was to provide a detailed analysis of the health literacy of people with type 2 diabetes in relation to their daily self-care practices.

Design Nested qualitative study in the ERMIES randomised controlled trial testing a 2-year structured care in type 2 diabetes. First round of semidirected interviews at the beginning of the trial with thematic analysis of content. Second round at the completion with directed interviews guided by the first round's themes together with Health Literacy Questionnaire.

Settings Interviews conducted at home.

Participants Forty-four (31 females/13 males, 30–79 years, glycated haemoglobin (HbA1c)≥7.5%) consecutive participants out of 100 recruited in the ERMIES trial from 4 diabetology outpatient settings (Reunion Island). Forty-two respondents to the second round interviews.

Results Three poles structured into eight themes characterised practices in context: health knowledge, disease management, expertise and social support. The relationships of participants in each of the eight themes were differentiated, ranging from functional to interactive and critical. Treatment and follow-up were essentially functional, while diet and exercise remained more interactive. Social support and relationship to health professionals were important determinants of disease management.

Conclusions Treatment management and disease monitoring remain primarily the job of health professionals, as opposed to diet, physical activity and social support being part of ordinary practice. Decision-making, as a shared social task, as well as resources for participation in health services, should be considered for relevant interventions in type 2 diabetes.

Trial registration number NCT01425866.

INTRODUCTION

Long-term management of diabetes is challenging.[1 2] People with type 2 diabetes struggle with the everyday constraints, treatment adherence and monitoring.[3–6] 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.[7–11] 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 between 2001 and 2007, the French ENTRED study has shown that only 17% of people with type 2 diabetes participated in self-management education, mainly in hospital setting.[13] Only 2% of persons treated for type 2 diabetes received all of the recommended monitoring regular exams and follow-up.[14] In contrast to a self-efficacy rated as high 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 characterised by a higher prevalence of complications despite good accessibility to quality care.[16 17]

Health literacy (HL) refers to the cognitive and social skills which determine the ability of individuals to gain access to, understand, remember and use information in ways which

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This longitudinal qualitative study examined health literacy and health practices in vulnerable people struggling with uncontrolled type 2 diabetes enrolled in a 2-year structured intensive managed care.
⇒ Interviews were conducted at home, considering the social contexts of health literacy related to disease management in real life, and health literacy needs were assessed too via the multidimensional Health Literacy Questionnaire.
⇒ The study took place in Reunion Island characterised by deeper social disparities compared with mainland France and the studied population was mainly female, with few included men.

promote and maintain good health.[18 19] HL has been linked to numerous health indicators and outcomes[20] and is a potential key component of health perceptions and practices.[21–23] In diabetes, HL has been mainly assessed through functional tests of reading ability, understanding and/or numeracy and has been linked to numerous outcomes.[24] Beyond functional HL, communicative and critical HL are central.[25] Communicative HL skills integrate the complex cognitive and social skills needed to perform daily activities, to extract information and infer meaning from different forms of communication, to apply new information to changing circumstances, and to interact with health services. Critical literacy refers to skills that can be applied to analyse critical information and adapt to better control life situations.

Understanding the complex interplay of self-care practices in diabetes in the light of HL skills and resources has been seldom explored.[26–29] Qualitative studies are needed to better understand the capacity and resources of individuals to implement health-relevant and meaningful practices and to adapt them to the strengths and limitations of the environments in which they are implemented. This study aimed to qualitatively analyse HL in its multiple dimensions in relation to self-care practices, in the context of structured care in four ambulatory diabetes care facilities in La Réunion.

METHODS
Study design and population
This study was part of the mixed ERMIES randomised controlled trial. The main objective of ERMIES was to evaluate the efficacy of a structured self-management education intervention in undercontrolled type 2 diabetes (glycated haemoglobin (HbA1c)>7.5%).[30] Out of 4 diabetology outpatient settings of the island of Reunion, 100 people were included between October 2011 and November 2014.[30 31] Participants of both arms benefited from a structured initial group education course conducted by trained educators, blind to the subsequent group allocation, within the 12 weeks following inclusion (online supplemental appendix 1). The intervention group was invited every 4 months to attend a structured group session. All included participants attended a quarterly medical follow-up in the diabetology unit during the study period (96 weeks).

The nested qualitative study included 44 subjects. Interviews were conducted in 2012 with the first 44 consecutive participants included in ERMIES who agreed to participate in the qualitative study. Among the 44 included the nested qualitative study, 42 participated to the second-round interviews in 2015, and 2 declined. Five out of 42 dropped out from the trial (online supplemental appendix 2) but accepted to respond to the second-round interviews.

When included, all participants were informed of the conditions of the research. They signed a written consent for a qualitative study by means of interviews conducted in their homes. At the time of the appointment (before each interview), a new information with oral agreement was given.

Participant and public involvement in research
Participants were not involved in setting the research question; nor did they participate in the design or implementation of the qualitative study. No participants were asked to advise on interpretation or writing up of results. However, during the second round of interviews, the results of the first-round interview's analysis were exposed and discussed with some participants who wished to do so.

The results of the research will be provided to study participants, and to local stakeholders, in order to join in the HL needs assessment as part of the eLS-OIIS project, whose objective is to help adapting health services responsiveness to persons with chronic diseases in Reunion island.[32]

Qualitative study
First round of interviews
The research involved two research assistants trained in the socioanthropological approach. The work on the interviews and analyses was built up through teamwork and regulated as the research developed, taking into account the contexts in which the participants were interviewed. The analyses of all the interviews were carried out by the two researchers independently of each other: these analyses were then crossed, discussed and reinterpreted in the event of differing interpretations. The result thus corresponds not to a single interpretation of the data, but to an intelligibility constructed, negotiated and regulated within the team, at every stage of the scientific process. Interviews, 1 hour each on average, were conducted at the participants' homes and focused on diabetes, self-monitoring, access to information, relationships to education and learning, participant positioning, decision-making, environment and support. The participants were invited to describe their behaviour in hospital, domestic and occupational settings, and in sociocultural 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 healthcare providers (HCPs) and services. The usual sociodemographic data and information about diabetes (duration, HbA1c, self-management of blood glucose, treatment, complications) were collected from the participants at the time of the first-round interviews.

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 investigated through thematic discourse analysis understood as communication patterns of both a social and linguistic nature.[33] The categories and signifiers were developed using the constant comparison method.[34] 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 analysis was carried out using the NVivo V.10 QSR International qualitative analysis software. Several themes constituting the management of diabetes in the ordinary context could be determined. For each of these themes, we identified three types of relationships in reference to the categories of HL established by Nutbeam:[25]

▶ A 'functional relationship to …', that is, 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 mobilises 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 to 42 participants (2 out of the 44 declined the interview). This grid (online supplemental appendix 3), covering the eight themes and the three 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.

The coding and analysis were subjected to a triangulation process carried out by three members of the research team (DB, JC-S and MB-D). 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 intraindividual and interindividual 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). Hence, it was possible to describe the individual changes and the evolution of the type of relationship (functional, interactive, critical) for each of the 8 themes from first to second rounds.

The inter-rater reliability of the coding of the type of relationship (functional, interactive, critical) to the themes was 62%. When the coding was discordant, the three researchers confronted their points of view to reach a consensus.

During the second round in 2015, HL was assessed using the Health Literacy Questionnaire (HLQ) for 39 of the 42 participants. The HLQ is a multidimensional questionnaire with robust psychometric properties,[19] translated and validated in French,[35] and composed of 44 items exploring HL through 9 independent scales of 4–6 items (online supplemental appendix 4). The individual score for each scale is calculated as the mean of the corresponding items.

RESULTS

Sociodemographic and clinical characteristics of the 44 participants are described in table 1. The gender distribution (31 of 44 were females) was roughly the same as the overall ERMIES trial population (67%) as well as median age, education, employment and income.

First-round interviews

Day-to-day management of the disease took place in a variety of forms and contexts: at home, in the family, in the healthcare context or setting, during leisure time or in the socioprofessional sphere. A set of eight themes could be individualised from the coding of the interviews that constituted the ordinary management of diabetes. These eight themes are grouped into three poles which interact through complex dynamics (table 2).

The consistency of the individual work through these eight themes, its continuity and its inclusion in the different relationships (functional, interactive or critical) were, to varying degrees according to the participants, constitutive of the management of health and illness (figure 1).

Health knowledge and access to knowledge

Relationship to knowledge and access to knowledge was primarily functional (for 29 out of 44 participants).

> 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 yr, retreated)

For some participants, the relationship to knowledge was more interactive (n=11). Participants were able to make connections between at least two elements, such as the links between diabetes and a balanced diet or regular physical activity.

Regarding access to knowledge, 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

Table 1 Sociodemographics and clinical characteristics of the sample (n=44)*

		All n=44	Intervention n=23	Control n=21
Sex	F/M	31/13	14/9	17/4
Age (years)	(30–49)	9	4	5
	(50–59)	12	8	4
	(60–69)	12	4	8
	(70–79)	11	7	4
Household composition	Live alone	13	8	5
	Live alone, with children	4	2	2
Education level	Primary school or less	9	7	2
	Middle school	24	11	13
	High school	6	2	4
	University undergraduate	5	3	2
Occupational status	Full-time or part-time employment	13	5	8
	Unemployed	12	8	4
	Retired	19	10	9
Income	Less than €1200	29	15	14
	€1200–€1999	7	4	3
	€2000–€3999	7	3	4
	≥€4000	1	1	0
Literacy	Difficulties in reading/writing	10	5	5
Diabetes, known duration	<9 years	11	7	4
	10–19 years	19	8	11
	≥20 years	14	7	7
HbA1c at inclusion	7.5%–7.9%	8	5	3
	8%–8.9%	20	8	12
	9.0%–11.9%	16	10	6
Diabetes treatment at inclusion	Oral agents (±GLP1 agonists)	20	10	10
	Insulin (±oral ± GLP1 agonists)	24	13	11
Self-monitoring of blood glucose	Once a day, fasting	15	10	5
	2–3 times a day, before meals	15	6	9
	Before and after meals	14	7	7
Known complications	Renal	18	13	5
	Heart	10	7	3
	Eye	2	1	1
	Feet	5	3	2
	Arteries	9	6	3
	None	14	6	8

*Among participants in the control group who participated to the first round of interviews, 2 declined the second-round interview: 1F, 50 years, full-time employment, €2000–€3999, middle school, diabetes >20 years duration, insulin, HbA1c 8%–8,9%, SMBG 6 per day, no complications; 1M, 62 years, retreated, €1200–€1999, high school, diabetes 10–19 years, oral agents, HbA1c 8%–8,9%, SMBG 3 per day preprandial, complications: heart, arteries.
F, female; GLP1 agonist, glucagon-like peptide 1 agonist; HbA1c, glycated haemoglobin; M, male; SMBG, self monitoring of blood glucose.

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.

Only two 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,

Table 2 The three main poles and eight themes of disease management issues

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

but you have to know if it's gold, real or synthetic. (Damien, 73 yrs, retreated)

The 'ordinary' management of disease
Food and exercise
Many participants (24/44) exhibited a 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.

Others (14/44) were more interactive:

I even get to correct something when I make a mistake at 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 almost don't put oil in it
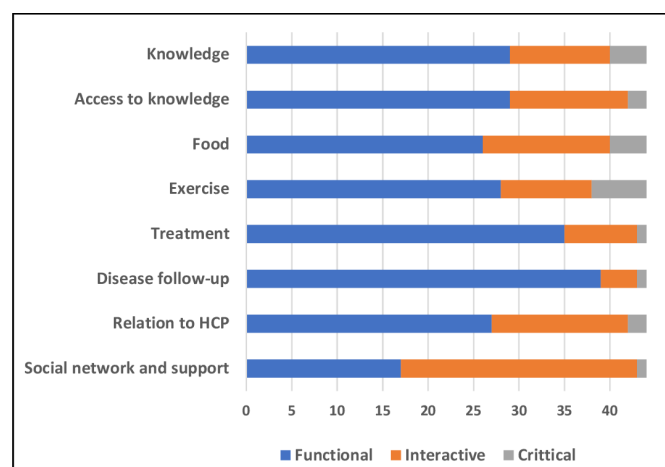
Figure 1 Disease management. functional, interactive and critical relationships to the eight themes. First-round interviews, n=44. HCP, healthcare provider.

because toothfish is already a fish that is fatty, even if it's good fat. Blandine, 57 yrs, account manager.

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

I go to the health network for sport 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, … Irène, 69 yrs, retreated.

Treatment and monitoring
The relationship to treatment and monitoring was functional for the majority of 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 has prescribed it for us… (Charles, 56 yrs, Gardien)

So the doctor can check the blood sugar level: it's how high and all that,… (Brigitte, 62 yrs, retreated)

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

On Tuesday, I had 1 hour of Taiichi, my test was 1.30 in the morning, 2.04 after breakfast, 1.31 at noon. I did Taiichi, 1.96 after lunch, so the benefit of Taiichi continues.[…] Wednesday I was at 1.59 and after breakfast I was at 3.02 but I know why: I ate a banana […] at noon I went shopping […] I left my car as far away as possible so that I could walk, […] (Ludivine, 73 yrs, retreated)

Only one participant exhibited critical relationship to treatment and monitoring:

I have my insulin, three injections a day and then I check with the meter […] If necessary, I'll do other checks during the day, […] 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 had hypoglycemia'. (Guillaume, 66 yrs, retreated, artist)

Expertise, support and social network
The relationships with HCP was functional for 26/44.

There's the nurse who comes to prep my medicine […], I just didn't understand, because I can't read very well, so I used to take the drugs in a mess, any way … (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 […] 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 one 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 crystallises 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 frequently 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 with 42 participants at the beginning and at the end of the ERMIES study highlighted the changes over time in the variables that make up the relationship with disease management, but in different ways according to individuals and contexts. The two participants who declined the second interview, but completed the trial, were both in the control group, and exhibited at the first-round interview a functional relationship to all themes except social support that was interactive.

Overall, health knowledge and access to knowledge evolved into a more interactive and critical relationship among participants, slightly more markedly in the intervention group. The most notable change was observed in the management aspects, particularly in relation to food, with many participants shifting from a functional to an interactive relationship (figure 2). With regard to physical activity, the many shifts from interactive to critical showed that participants understood the benefits of physical activity and were able to better integrate it into their

practices. For these two themes, changes were observed in both the intervention and control groups. The move towards a more interactive or even critical posture was also objective for disease follow-up and monitoring, but here more so in the intervention group. However, the relationship to treatment remained mostly at a very functional level (28 out of 42) 'The nurse prepares that, and I take my oral medication. And I have the prescriptions for all the medicines I take it' (Marguerite, 79, retreated, intervention group), and few participants modulated and adjusted the treatment on their own regardless of the allocation group. There was a clear shift for many participants towards a more interactive relationship with HCP, slightly more in the intervention group. The relationship to social support was also less functional.

The five participants who dropped out from the trial were younger than those who completed the study, with low income, and two of them had difficulties in reading and writing. All five had an essentially functional relationship with treatment and follow-up of the disease, leaving the decision and conduct to the physician and other healthcare professionals, although two of them were interactive in their relationships with providers.

Table 3 displays the mean scores through the 9 dimensions of the HLQ for the 39 participants who filled in the questionnaire during the second round of interviews. Overall, the greatest difficulties were in having sufficient information to manage health (HLQ2), in appraising health information (HLQ5) for the first part of the questionnaire, in ability to find good health information (HLQ8) and in understanding well enough health information to know what to do (HLQ9) for the second part of the questionnaire. On the contrary, scores were higher for scale 1 'Feeling understood and supported by HCP' and scale 6 'Ability to actively engage with HCP'.

DISCUSSION

Both people with type 2 diabetes and HCP are confronted in the real world with the daily and long-term management of the disease.[4 36 37] HL is a potential determinant in attaining lifestyle behaviour, medication adherence and adequate monitoring of the disease.[38 39] This qualitative study, in which 86 interviews were conducted at the initiation and after the completion of a structured 2-year follow-up, showed the multidimensional nature of HL in relation to self-care practices and disease management. Ordinary management of diabetes consisted of distinct postures for lifestyle behaviours on one side, and for medical aspects on the other: participants mainly had 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 functional for treatment and monitoring, while being interactive or even critical for exercise and diet. Social support and patient–provider relationship were important elements associated with a more interactive posture as regard to disease management.
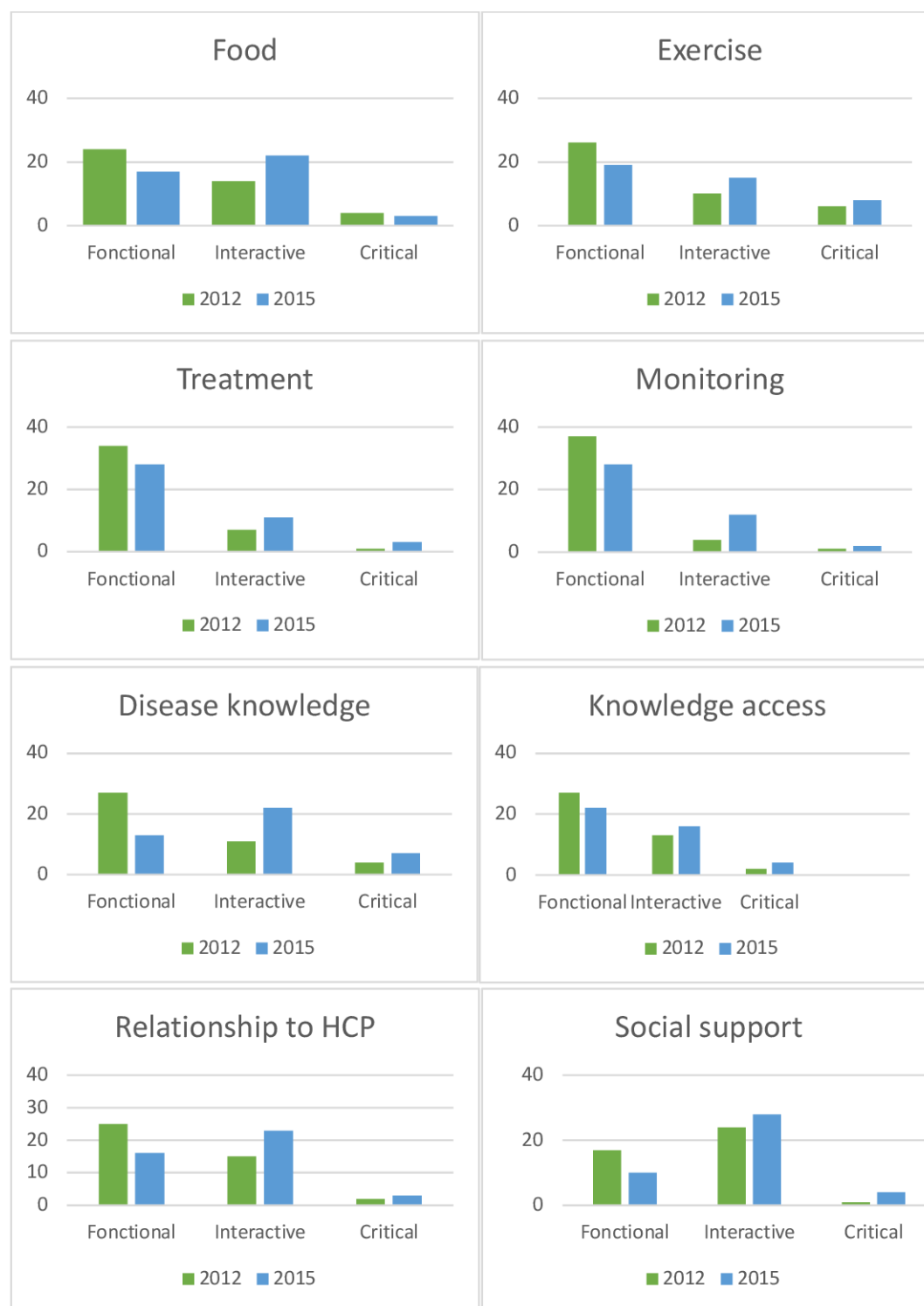
Figure 2 Number of patients with functional, interactive and critical relationships to the eight themes of disease management in 2012 (first-round interviews) and 2015 (second round interviews). Ermies ethnosocio study, qualitative thematic analysis of interviews, n=42 participants. HCP, healthcare provider.

In this study, a fine qualitative approach of disease management analysed through the theoretical lens of the Nutbeam's HL scheme yielded useful insights for a comprehensive description of strengths and weaknesses at the individual and contextual level for people struggling with disease management.[25] The HLQ was used as a complement to describe the HL needs expressed by participants. The HLQ is a validity driven questionnaire and grounded in real-world settings.[19] Correspondence with the HL profiles using the 9 scales of the HLQ should be cautious and grasped in a complementary way. Indeed, the qualitative data were strengthened by the higher scores on the HLQ scales related to HCP and services (Feeling understood and supported by HCP,

Table 3 Health Literacy Questionnaire (HLQ) profiles of the sample (n=39)

HLQ scales		Mean (SD) (95% CI)
	First part of the questionnaire	Scores 1–4*
1	Feeling understood and supported by healthcare professionals	3.31 (0.53) (3.15 to 3.48)
2	Having sufficient information to manage my health	3.05 (0.63) (2.85 to 3.25)
3	Actively managing my health	3.16 (0.45) (3.02 to 3.30)
4	Social support for health	3.03 (0.54) (2.86 to 3.20)
5	Appraisal of health information	2.95 (0.54) (2.78 to 3.12)
	Second part of the questionnaire	Score 1–5†
6	Ability to actively engage with healthcare professionals	3.87 (0.63) (3.68 to 4.07)
7	Navigating the healthcare system	3.72 (0.70) (3.50 to 3.94)
8	Ability to find good health information	3.34 (0.69) (3.12 to 3.55)
9	Understand health information enough to know what to do	3.52 (0.79) (3.27 to 3.76)

*Response options from 1—strongly disagree—to 4—strongly agree.
†Response options from 1—cannot do or always difficult—to 5—always difficult.

HLQ1, Ability to actively engage with HCP, HLQ6, Navigating the healthcare system, HLQ7), and lower scores on the HLQ scales related to health information (having, finding, appraising). Similar HLQ profiles were found in community-dwelling people with type 2 diabetes in Australia, with the highest scores in dealing with HCP (HLQ1, HLQ6), and the lowest in having, appraising or finding health information (HLQ2, HLQ5, HLQ8).[40]

In this population of participants struggling with insufficiently controlled type 2 diabetes, our results highlight the predominant perceptions and attitude regarding treatment and monitoring remaining under the expertise of HCP. O'Connor *et al*[41] reported that people with diabetes 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.[42] Timely information and support from HCP, adapted to the actual individual constraints allow sustainable efforts for self-management.[43]

Studies have shown difficulties in actively managing health, health information finding, understanding and appraisal, as well as ability to engage with HCP.[19 40 44] Using the HLQ, Friis *et al*[45] reported the high treatment burden in persons with chronic multimorbidity and difficulties in understanding health information. This is in line with the apparent contrast found in this 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.[46] Moreover, persons with diabetes lacked understanding of what to do faced to blood glucose results, as what could be noticed too here.

This qualitative study highlights the potential shift from functional to interactive or even critical attitude obtained after a 2-year long integrative care including structured self-management education in people with poorly controlled diabetes. Other studies have shown the role of interactive and critical HL in successful self-management of chronic disease.[16] However, this shift highly differs by individual, medical, healthcare and social contexts.[16 47] Taking into account HL profiles and adapt self-management education to these HL needs is crucial in chronic diseases.[3 48–50]

Social support appeared 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 49] 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 43] Low personal resources, for example, regarding the appropriation of health information, together with burdensome family and social situations may explain difficulties in engagement with self-management.[43]

Gender distribution of participants with most females is worth noting, and this was in line with the distribution in the whole ERMIES sample (67%). Lower inclusion rate of males vs women have been previously noticed in other studies in Reunion.[51–53] According to the national health insurance's data the prevalence of declared and/or treated diabetes in Reunion island is higher in women than in men (9.6% vs 7,9 %),[54] suggesting a possible underdiagnosis and a higher drop-out from care of type 2 diabetes in men. Beside

gender, qualitative data obtained here from drop-out participants, who were younger, with low income at the second-round interviews suggest greater difficulties regarding understanding and appraising health information, social support and interactions with HCP.

The main strength of this study is its longitudinal design, with interviews repeated after the completion of a structured managed care and a multidimensional HL assessment via the HLQ. 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. Nevertheless, this study has some limitations. First, it took place during a comparative intervention trial with structured intensive managed care under the coordination of specialised secondary outpatient centres, and in Reunion island, a French outmost territory, with deeper contrasted social disparities compared with metropolitan France. The studied population was mainly female, and the question of the lower implication of men in self-care was difficult to analyse. 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 education course. The second round interviews took place after 2 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 should be the subject of a process of appropriation in which the particular contexts should be apparent.

This longitudinal qualitative study in vulnerable participants struggling with type 2 diabetes and low HL, shows that decision making, handling of treatment and disease monitoring remains primarily the purview of HCP. Not all self-care practices are equivalent in terms of awareness, understanding their usefulness and appraising their effect. Moreover, the ability and the willingness of engaging in some self-practices like self-monitoring, follow-up awareness and treatment adjustment is often weak. However, this seemingly passive attitude is counterbalanced by feeling supported and trusted by HCP and is not inconsistent with an otherwise active attitude of engaging in lifestyle behaviours. For the latter, social support and shared social tasks are critical. HCP have a key role in helping chronically ill people to take long-term control of health information and services, while bearing in mind the prevalent functional relationship with monitoring and treatment adaptation.

The multidimensional nature of diabetes management and of HL, both embedded in social configurations, has to be acknowledged. Conceiving and designing interventions and services aiming at improving diabetes self-management should take into account these dimensions of self-care and assess the differentiated HL dimensions according to individual variations and contexts.

ORCID iD
Xavier Debussche http://orcid.org/0000-0003-3087-4297

REFERENCES

1 Wang CY, Neil DL, Home P. Vision – an overview of prospects for diabetes management and prevention in the next decade. *Diabetes Res Clin Pract* 2018:101–12.
2 Zheng Y, Ley SH, Hu FB, . Global aetiology and epidemiology of type 2 diabetes mellitus and its complications. *Nat Rev Endocrinol* 2018;14:88–98.
3 Balcou-Debussche M, Debussche X. Hospitalization for type 2 diabetes: the effects of the suspension of reality on patients' subsequent management of their condition. *Qual Health Res* 2009;19:1100–15.
4 Hinder S, Greenhalgh T. "This does my head in". Ethnographic study of self-management by people with diabetes. *BMC Health Serv Res* 2012;12:83.
5 Davies MJ, D'Alessio DA, Fradkin J, *et al*. Management of hyperglycemia in type 2 diabetes, 2018. A consensus report by the American diabetes association (ADA) and the European association for the study of diabetes (EASD). *Diabetes Care* 2018;41:2669–701.
6 Debussche X. Is adherence a relevant issue in the self-management education of diabetes? a mixed narrative review. *Diabetes Metab Syndr Obes* 2014;7:357.
7 Haas L, Maryniuk M, Beck J, *et al*. National standards for diabetes self-management education and support. *Diabetes Care* 2014;37 Suppl 1:S144–53.
8 Chatterjee S, Davies MJ, Heller S, *et al*. Diabetes structured self-management education programmes: a narrative review and current innovations. *Lancet Diabetes Endocrinol* 2018;6:130–42.
9 Lawton J, Peel E, Parry O, *et al*. Lay perceptions of type 2 diabetes in Scotland: bringing health services back in. *Soc Sci Med* 2005;60:1423–35.
10 Pamungkas RA, Chamroonsawasdi K, Vatanasomboon P. A systematic review: family support integrated with diabetes self-management among uncontrolled type II diabetes mellitus patients. *Behav Sci* 2017;7:1–17.
11 American Diabetes Association. 1. Improving Care and Promoting Health in Populations: *Standards of Medical Care in Diabetes-2018*. *Diabetes Care* 2018;41:S7–12.
12 Chevreul K, Berg Brigham K, Bouché C. The burden and treatment of diabetes in France. *Global Health* 2014;10:6.
13 Fournier C, Gautier A, Mosnier-Pudar H, *et al*. ENTRED 2007: results of a French national survey on self-management education to people with diabetes… still a long way to go! *Ther Patient Educ* 2014;6:10102.
14 Robert J, Roudier C, Poutignat N. Prise en charge des personnes diabétiques de type 2 en France en 2007 et tendances PAR rapport 2001. *Bull Epidemiol Hebd* 2009:455–60.
15 Tiv M, Viel J-F, Mauny F, *et al*. Medication adherence in type 2 diabetes: the ENTRED study 2007, a French population-based study. *PLoS One* 2012;7:e32412.
16 Fosse-Edorh S, Fagot-Campagna A, Detournay B, *et al*. Impact of socio-economic position on health and quality of care in adults with type 2 diabetes in France: the Entred 2007 study. *Diabet Med* 2015;32:1438–44.
17 Debussche X, Pholsena M, Fournier A, *et al*. [High prevalence of proteinuric nephropathy screened in patients with type 2 diabetes consulting community-based general practitioners in French overseas departments and territories. ALBUM study]. *Rev Prat* 2014;64:761-6.
18 Kickbusch I, Pelikan JM, Apfel F. Health literacy : The solid facts. World Health Organisation Europe, 2013. Available: http://www.euro.who.int/en/publications/abstracts/health-literacy.-the-solid-facts
19 Osborne RH, Batterham RW, Elsworth GR, *et al*. The grounded psychometric development and initial validation of the health literacy questionnaire (HLQ). *BMC Public Health* 2013;13:658.
20 Dewalt DA, Berkman ND, Sheridan S, *et al*. Literacy and health outcomes: a systematic review of the literature. *J Gen Intern Med* 2004;19:1228–39.
21 Aaby A, Friis K, Christensen B, *et al*. Health literacy is associated with health behaviour and self-reported health: a large population-based study in individuals with cardiovascular disease. *Eur J Prev Cardiol* 2017;24:1880–8.
22 Gazmararian JA, Kripalani S, Miller MJ, *et al*. Factors associated with medication refill adherence in cardiovascular-related diseases: a focus on health literacy. *J Gen Intern Med* 2006;21:1215–21.
23 Shiyanbola OO, Unni E, Huang Y-M, *et al*. The association of health literacy with illness perceptions, medication beliefs, and medication adherence among individuals with type 2 diabetes. *Res Social Adm Pharm* 2018;14:824–30.
24 Al Sayah F, Williams B, Johnson JA. Measuring health literacy in individuals with diabetes: a systematic review and evaluation of available measures. *Health Educ Behav* 2013;40:42–55.
25 Nutbeam D. The evolving concept of health literacy. *Soc Sci Med* 2008;67:2072–8 http://www.sciencedirect.com/science/article/pii/S0277953608004577
26 Balcou-Debussche M. *De l'éducation thérapeutique du patient la littératie en santé. Problématisation socio-anthropologique d'objets didactiques contextualisés*. Paris: Editions des Archives Contemporaines, 2016.
27 Samerski S. Health literacy as a social practice: social and empirical dimensions of knowledge on health and healthcare. *Soc Sci Med* 2019;226:1–8.
28 Sarkar U, Karter AJ, Liu JY, *et al*. The literacy divide: health literacy and the use of an Internet-based patient portal in an integrated health system-results from the diabetes study of northern California (distance). *J Health Commun* 2010;15 Suppl 2:183–96.
29 Rowsell A, Muller I, Murray E, *et al*. Views of people with high and low levels of health literacy about a digital intervention to promote physical activity for diabetes: a qualitative study in five countries. *J Med Internet Res* 2015;17:1–12.
30 Debussche X, Collin F, Fianu A, *et al*. Structured self-management education maintained over two years in insufficiently controlled type 2 diabetes patients: the ERMIES randomised trial in reunion island. *Cardiovasc Diabetol* 2012;11:91.
31 Debussche X, Balcou-Debussche M. Analyse des profils de littératie en santé chez des personnes diabétiques de type 2 : la recherche ERMIES-Ethnosocio. *Sante Publique* 2018;30:157–68.
32 Bakker MM, Putrik P, Aaby ASE, *et al*. Acting together – who National health literacy demonstration projects (NHLDPs) address health literacy needs in the European region. *Public Heal Panor* 2019;5:233–43.
33 Ritchie J, Lewis J. *Qualitative research practice: a guide for social scientists and researchers*. London: SAGE, 2003.
34 Glaser BG, Strauss AL. *The discovery of Grounded theory*. Chicago, IL: Aldine, 1967.
35 Debussche X, Lenclume V, Balcou-Debussche M, *et al*. Characterisation of health literacy strengths and weaknesses among people at metabolic and cardiovascular risk: validity testing of the health literacy questionnaire. *SAGE Open Med* 2018;6:2050312118801250.
36 Lawton J. Lay experiences of health and illness: past research and future agendas. *Sociol Health Illn* 2003;25:23–40.
37 Balcou-Debussche M. *L'éducation des malades chroniques. Une approche ethnosociologique*. Paris: Éditions des Archives Contemporaines, 2006.
38 Greenhalgh T. Health literacy: towards system level solutions. *BMJ* 2015;350:h1026.
39 Heijmans M, Waverijn G, Rademakers J, *et al*. Functional, communicative and critical health literacy of chronic disease patients and their importance for self-management. *Patient Educ Couns* 2015;98:41–8.
40 Goeman D, Conway S, Norman R, *et al*. Optimising health literacy and access of service provision to community Dwelling older people with diabetes receiving home nursing support. *J Diabetes Res* 2016;2016:1–12.
41 O'Connor PJ, Crabtree BF, Yanoshik MK. Differences between diabetic patients who do and do not respond to a diabetes care intervention: a qualitative analysis. *Fam Med* 1997;29:424–8.
42 Campbell R, Pound P, Pope C, *et al*. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med* 2003;56:671–84.
43 Frost J, Garside R, Cooper C, *et al*. A qualitative synthesis of diabetes self-management strategies for long term medical

outcomes and quality of life in the UK. *BMC Health Serv Res* 2014;14:348.

44 Friis K, Lasgaard M, Osborne RH, *et al*. Gaps in understanding health and engagement with healthcare providers across common long-term conditions: a population survey of health literacy in 29,473 Danish citizens. *BMJ Open* 2016;6:e009627.

45 Friis K, Lasgaard M, Pedersen MH, *et al*. Health literacy, multimorbidity, and patient-perceived treatment burden in individuals with cardiovascular disease. A Danish population-based study. *Patient Educ Couns* 2019;102:1932-1938.

46 Peel E, Douglas M, Lawton J. Self monitoring of blood glucose in type 2 diabetes: longitudinal qualitative study of patients' perspectives. *BMJ* 2007;335:493.

47 Wang R-H, Hsu H-C, Lee Y-J, *et al*. Patient empowerment interacts with health literacy to associate with subsequent self-management behaviors in patients with type 2 diabetes: a prospective study in Taiwan. *Patient Educ Couns* 2016;99:1626–31.

48 van der Gaag M, Heijmans M, Spoiala C, *et al*. The importance of health literacy for self-management: a scoping review of reviews. *Chronic Illn* 2022;18:234–54.

49 Balcou-Debussche M. Social inscription of TPE, heterogeneity and patient's vulnerability. Analysis of results obtained in the plural context of Mayotte. *Educ Ther Patient/Ther Patient Educ* 2013;5:113–21.

50 Bakker MM, Putrik P, Rademakers J, *et al*. Addressing health literacy needs in rheumatology: which patient health literacy profiles need the attention of health professionals? *Arthritis Care Res* 2021;73:100–9.

51 Debussche X, Rollot O, Le Pommelet C, *et al*. Quarterly individual outpatients lifestyle counseling after initial inpatients education on type 2 diabetes: the REDIA Prev-2 randomized controlled trial in reunion island. *Diabetes Metab* 2012;38:46–53.

52 Favier F, Jaussent I, Moullec NL, *et al*. Prevalence of type 2 diabetes and central adiposity in La reunion Island, the REDIA study. *Diabetes Res Clin Pract* 2005;67:234–42.

53 Fianu A, Bourse L, Naty N, *et al*. Long-Term effectiveness of a lifestyle intervention for the primary prevention of type 2 diabetes in a low socio-economic community – an intervention follow-up study on reunion island. *PLoS One* 2016;11:e0146095–16.

54 Ndong JR, Romon I, Druet C, *et al*. Caractéristiques, risque vasculaire, complications et qualité des soins des personnes diabétiques dans les départements d'outre-mer et comparaison la métropole : Entred 2007-2010, France. *BEH* 2010.

Appendix 1. Self-management education course

1. Initial education cycle

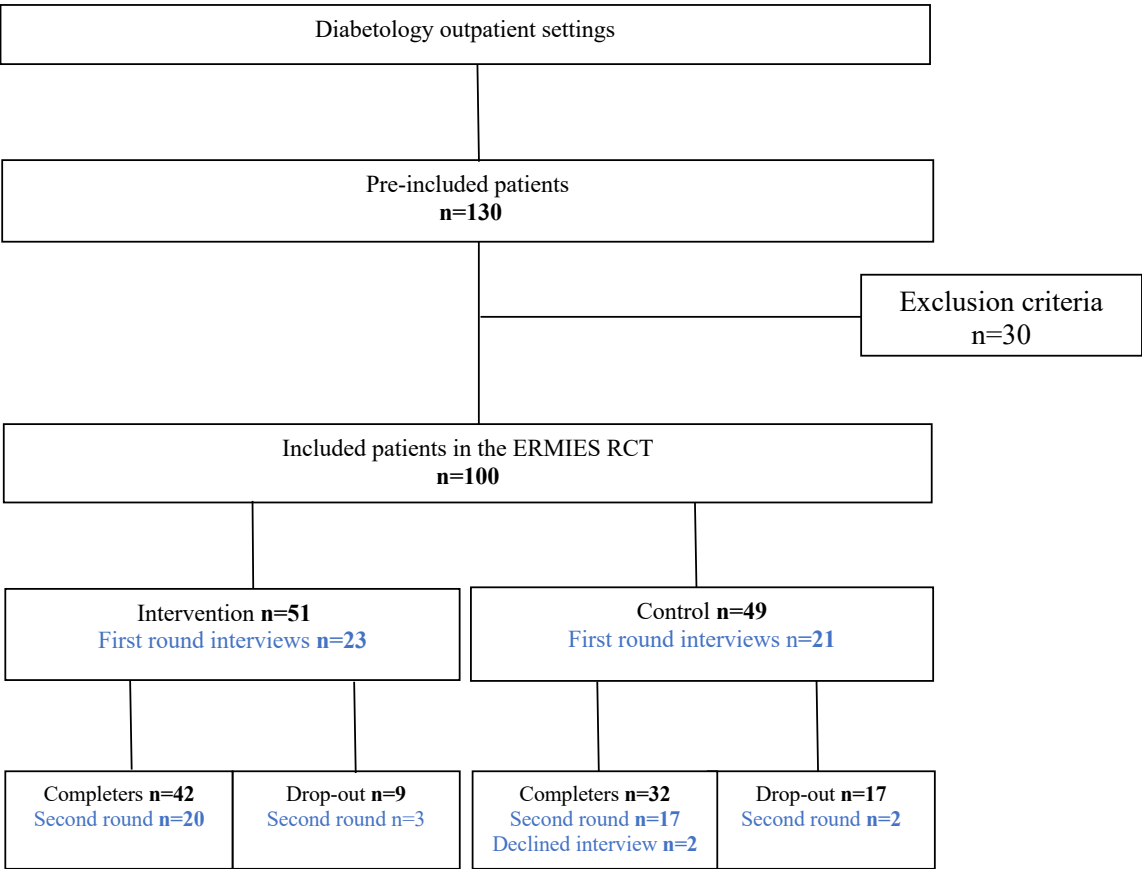The initial cycle consists of 3 to 7 educational weekly or bi-weekly 2-hour group sessions for 4 to 10 patients:

– Personalised assessment group session (120 minutes): patients work on their own clinical and biological factors that can influence health maintenance (blood glucose, blood pressure, lipids, weight, waist circumference, smoking), before looking at lifestyle measure effects and specific impacts of eventual changes. They then scrutinise the feasibility of action planning and implementation in real life, and goal-setting taking into account all individual, social, and contextual dimensions. At the end of this session, each learner can schedule 2 to 6 specific additional focused sessions, according his/her needs and goal-setting.

– Two to 6 specific additional focused sessions of 90 to 120 minutes, spaced at intervals of 1 to 2 weeks (3 weeks maximum). These sessions are selected on the six following themes: self-monitoring and adaptation of treatment - physical activity - food and control of fat intake – understanding of diabetes and treatment – challenges of insulin therapy – prevention of foot lesions.

2. On-going SME support:

. Personalised empowerment follow-up including group sessions of 90 to 120 minutes each, with three to ten patients at 16, 32, 48, 64, 80 and 96 weeks. Each session will be scheduled at the end of the previous session. Patients will work on the progress of their indicators as follows: medical (HbA1c levels, blood sugar, arterial pressure, lipids, waist circumference, smoking, treatments); health coping and goal setting (action(s) initially decided on, actual implementation, obstacles); cognitive (review of knowledge gained through the first session assessment session and additional sessions). The summary of the session comprises objectives for action(s) to be implemented and the scheduling of optional additional sessions to support practical implementation.

Qualitative study nested in the ERMIES trial. Flow chart of participants

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Appendix 3

Functional, interactive and critical relationship to the 8 themes of disease management

Themes	Functional	Interactive	Critical
Physical activity	I walk or move every day because I've been told to be active for diabetes	I am physically active because it improves my diabetes	I am physically active whenever possible, in relation to the life I have in hand (not only because of my diabetes). Being active is really good for me
Food	When I buy food and cook, I do try to respect the recommendations I received (from the doctor, the dietician...)	I understand that food should be balanced and diversified: I adjust my diet as best I can according to the situations of everyday life	Eating a balanced diet does not mean you have to deprive yourself. With the disease, I learned to buy and cook differently, while taking into account the cost, tastes, desires and availability of food
Treatment	I try to follow the treatment prescribed to me as best I can	I follow my treatment as best I can because I realize that it is useful	I know the role of each treatment and I adjust it according to the type of life I have, so as to achieve as good a balance as possible
Follow-up	I keep up with my diabetes on a daily basis and show my results to my doctor regularly	I test when I can and discuss my diabetes care with my doctor (or other provider).	Once I understood diabetes and its evolution, I can live a normal life, while having regular tests to avoid complications.
Social support and network	I try not to bother anyone with my illness	I realize that I am not alone and that I can count on others	I just live like everyone else and I nearly forget that I have diabetes
Relation to health care providers	I do whatever my doctor (or other provider) tells me	I have discussions with my doctor (or other) about diabetes because I want to understand what is going on	I know my diabetes and visit health care providers only when needed.
Access to knowledge	I stick to what my doctor says about my diabetes	Whenever I come across something about diabetes, I look	I don't listen to anything: I know where the sources are and I stick to that

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

		at it and try to get something out of it	
Knowledge	Diabetes is something that's wrong: it's not up to me or what I do	Diabetes is one or more things that need to be monitored independently of each other, but which I can do something about (e.g. diet and/or physical activity, etc.).	Diabetes is a set of interacting elements (the body, the organs, the environment, etc.) that puts me at risk of complications if I don't pay attention, but that I can also stabilise (or improve) if I monitor all these elements at the same time, taking into account the life I lead

Appendix 4. Health Literacy Questionnaire scales.

HLQ scale	1st part of the questionnaire	
	Response options from 1 -strongly disagree- to 4 -strongly agree-	
HLQ 1	**Feeling understood and supported by healthcare professionals**	4 items
HLQ 2	**Having sufficient information to manage my health**	4 items
HLQ 3	**Actively managing my health**	5 items
HLQ 4	**Social support for health**	5 items
HLQ 5	**Appraisal of health information**	5 items

HLQ scale	2nd part of the questionnaire	
	Response options from 1-cannot do or always difficult- to 5 -always	
HLQ 6	**Ability to actively engage with healthcare professionals**	5 items
HLQ 7	**Navigating the healthcare system**	6 items
HLQ 8	**Ability to find good health information**	5 items
HLQ 9	**Understand health information enough to know what to do**	5 items