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► To cite this version:

Xavier Debussche, Maryvette Balcou-Debussche, Delphine Ballet, Jessica Caroupin. Health literacy in context: struggling to self-manage diabetes. A longitudinal qualitative study. 2020. hal-03066032

HAL Id: hal-03066032

<https://hal.univ-reunion.fr/hal-03066032>

Preprint submitted on 15 Dec 2020

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Health literacy in context: struggling to self-manage diabetes. A longitudinal qualitative study

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Research Article

Keywords: Health literacy, healthcare pathways, health behaviours, type 2 diabetes, patient-provider relationship, self-care, Health Literacy Questionnaire (HLQ)

DOI: <https://doi.org/10.21203/rs.3.rs-24192/v2>

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Abstract

Objective

Considering health literacy is a key element for health service responsiveness to self-management needs in diabetes. This qualitative study aimed to provide a detailed analysis of the health literacy of people with type 2 diabetes in relation to their daily self-care practices.

Methods

Interviews (n=86) were conducted as part of the qualitative study ERMIES-ethnosocio, at the beginning and at the end of a structured educational care. The interviews focused on food practices, exercise, treatment, relationship to health information and professionals.

Results

Three poles structured into eight themes characterized 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.

Conclusion and Practice implications

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.

Introduction

Long term management of diabetes and prevention of complications is challenging [1,2]. Patients struggle with the everyday constraints, treatment adherence, and follow-up 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 type 2 diabetes patients participated in self-management education, mainly in hospital setting [13]. Only 2% of treated diabetic patients received all of the recommended monitoring regular exams and follow-up [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 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 promote and maintain good health [18]. HL has been linked to numerous health indicators and outcomes [19] and is a potential key component of health perceptions and practices [20–22]. In diabetes, HL has been mainly assessed through functional tests of reading ability, understanding, and/or numeracy and has been linked to numerous outcomes [23]. Beyond functional HL, communicative and critical HL are central [24]. 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 [25,26]. Qualitative studies are needed to better understand the capacity 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. The present study aimed to qualitatively analyse health literacy in its multiple dimensions in relation to self-care practices, in the context of structured care in 4 ambulatory diabetes care facilities in La Réunion.

Methods

2.1 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 of a structured self-management education intervention in under-controlled type 2 diabetes ($HbA1c > 7.5\%$). Out of 4 diabetology outpatient settings of the island of Reunion, 100 people were included between October 2011 and November 2014 [27,28]. Participants underwent a 3-month self-management education course, and then attended quarterly a medical and biological check-up for 2 years. The 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 ethical agreement of the CPP Sud Ouest Outremer III 20/01/2011, amendment of 10/05/2011 for the nested longitudinal qualitative study.

2.2 Qualitative study

2.2.1 First round of interviews

Research assistants conducted the interviews, one hour each on average, at the participants' homes. Interviews 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 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 [29]. Categories and signifiers were developed using the constant comparison method [30]. 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 HL established by Nutbeam [24] :

- 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.

2.2.2 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 the 8 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.

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 cross-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).

During the second round in 2015, HL was assessed too using the Health Literacy Questionnaire (HLQ) for 39 participants among 42. The HLQ is a multidimensional questionnaire with robust psychometric properties [31], translated and validated in French [32], and composed of 44 items exploring 9 dimensions of HL (Table 1).

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.

3.1 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 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 the interviews that constituted the ordinary management of diabetes. These 8 themes are grouped into 3 poles which interact through complex dynamics (table 3).

The consistency of the individual work through these 8 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. (fig 1).

3.1.1 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 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 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)

3.1.2 The 'ordinary' management of disease

3.1.2.1 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.

However, one third (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 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.

3.1.2.2 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)

3.1.3 Expertise, support and social network

3.1.3.1 The relationships with health care providers 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 ... 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 [...] 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).

3.1.3.2 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 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).

3.2 Second round of interviews

The interviews conducted twice 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.

Overall, health knowledge and access to knowledge exhibited a shift towards a more interactive and critical relationship among participants. The most important evolution was observed on the management aspects, particularly regarding food, with lot of participant moving functional to interactive (fig 2). With regard to physical activity, the many passages from interactive to critical showed that participants understood the benefits of physical activity and were able to better integrate it into their practices. The move towards a more interactive or even critical posture was also objective for disease follow-up and monitoring. However, the relationship to treatment remained mostly at a very functional level (28 out of 42) and few participants modulated and adjusted the treatment on their own. There was a clear shift for many participants towards a more interactive relationship with HCP. Social support was also less functional.

Fig.3 displays the repartition of scores for each scale of the Health Literacy Questionnaire for the 39 participants who filled in the questionnaire during the second round of interviews. Overall, the greatest difficulties were in having, finding, using or appraising health information: 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).

Discussion And Conclusion

4.1 Discussion

In diabetes, both patients and HCP are confronted in the real world with the daily and long-term management of the disease. [4,33,34]. HL is a potential determinant in attaining lifestyle behaviour, medication adherence, and adequate monitoring of the disease [35,36]. 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. These results were strengthened by 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 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 [37] reported 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 [38]. Timely information and support from HCP, adapted to the actual individual constraints allow sustainable efforts for self-management [39].

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 [31,40,41]. Friis et al [42] 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 [43]. 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 [4,44]. 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 [3,39]. 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 [39].

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 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 should be the subject of a process of appropriation in which the particular contexts should be apparent.

4.2 Conclusion

This longitudinal qualitative study in vulnerable participants struggling with type 2 diabetes and low HL, shows that decision making and 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 and follow-up awareness, as well as treatment adjustment is often weak. However, this seemingly passive attitude is counterbalanced by feeling supported and trusted by health

care providers, 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.

4.3 Practice implications

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.

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 was given with oral agreement.

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 data. 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.

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. All authors read and approved the manuscript.

Acknowledgements

The authors wish to thank all the participants of the qualitative study, and all the staff from Hospital secondary centers and from the RéuCARE diabetes management network, engaged in the follow-up, education support, and treatment of participants recruited as well as in the logistic of the ERMIES study. Authors are grateful too to the team of the CIC-EC, and of the DRCI of the CHU de La Réunion, especially Liliane Cotte, Fideline Filleul, Vanessa Basque, Emilie Techer, for strong support of the ERMIES study.

ERMIES Investigators Study Group : Fawzi Bakiri, Maryvette Balcou-Debussche, Marie-Claude Boyer, Muriel Cogne, Xavier Debussche, François Favier, Adrian Fianu, Ania Flaus-Furmaniuk, Jean-Hugues Gatina, Nathalie Le Moullec, Victorine Lenclume, Jean-Christophe Maiza, Olivier Perrichot, Céline Regnier, Olivier Rollot, Stéphane Schneebeli, Yogananda Thirapathi, Jean-Luc Yvin. Members of the ERMIES Study Group were co-investigators and invested in the implementation and the conduct of the ERMIES RCT study.

Funding

This project received a grant from IRESP, French Research Institute in Public Health (AAP ETP 2013-03), and the ERMIES trial was funded by PHRC interregional, French Inter-regional Hospital Program for Clinical Research 2010 (GIRCI Sud Ouest OutreMer; French Ministry of Health). The sponsor institution of the 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.

Abbreviations

HCP: health care providers

HLQ: Health Literacy Questionnaire

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Tables

Table 1. Health Literacy Questionnaire scales.

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

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 ($\pm$ GLP1 agonists)	21
	Insulin ($\pm$ oral $\pm$ GLP1 agonists)	23
Self-monitoring of blood glucose	Once a day, fasting	15
	2- 3 times a day, before meals	15
	Before and after meals	14
Known complications	Renal	18
	Heart	10
	Eye	2
	Feet	5
	Arteries	9
	None	14

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 Monitoring
Expertise, support and social network	Relationships with professionals Health and social support

Figures

Figure 1

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

Figure 2

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.

Figure 3

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.