

Enhancing health literacy and behavioural change within a tele-care education and support intervention for people with type 2 diabetes

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Abstract

Background Behavioural change interventions for persons with chronic illness draw on a variety of theoretical approaches including motivational interviewing and shared decision making. Health literacy provides an additional, potentially powerful explanatory framework to guide research and practice.

Objective To examine the changes in the depth and detail of diabetes-related knowledge and confidence for persons with type 2 diabetes.

Design Two-year, prospective, observational study, using questionnaire data at two time points (baseline and 2 years later) and in-depth interviews with a theoretically selected subsample.

Setting and participants A total of 319 patients initially recruited from a deprived urban area in north-west England

Intervention Dedicated tele-carer education and support, tailored to the individual circumstances of the patient.

Main outcome measures Perceptions of confidence, levels of empowerment, learning for self-care and most helpful aspects of the intervention.

Results Over 90% expressed confidence in keeping their blood sugar controlled, and high levels of perceived empowerment (mean = 4.25; 95% CI, 4.17–4.33) were found. Changes in the depth and detail of diabetes-related knowledge and confidence, from the specific to the more general, were observed and enhanced competence in translating knowledge into practice.

Discussion and conclusions The intervention, built within a developed working partnership between tele-carer and patient, operated at two levels: health literacy, enhancing knowledge, developing personal skills and enabling self-control; and socio-psychological behavioural change, tailored to individuals within their socio-economic environments, enabling increased motivation and supportive problem-solving. Both approaches find reflection in the findings and provide powerful explanatory lenses to interrogate the data.

Context and background

Within health and medical care practice, behavioural change interventions routinely centre attention on individual patients, looking towards optimum strategies to promote and support individuals to modify their behaviour. Examples include use of motivational interviewing,¹ shared decision making,^{2,3} applications of the stages of change model⁴ and social cognition models drawing on the notion of 'intention' or 'readiness to change'.⁵ Yet other literature examines the context in which treatment and care is provided, in particular, promoting the notion of patient-centred care.⁶ While individual patient empowerment⁷ may be the ultimate goal, discussions tend to focus on adherence to prescribed programmes and ways to support persons to manage their own ill health.

Such strategies are particularly apposite in the field of diabetes where, to maintain healthy blood glucose levels, diabetes patients must adhere continually to a complex and often burdensome daily regimen that includes monitoring and self-regulation of diet, blood sugar levels, exercise and medication. Some programmes (most recently, the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) trial for persons with type 2 diabetes⁸) pursue a structured, one-off, short, group-education programme, drawing on a core set of theories relating to informed choice, empowerment, and social learning theory. However, systematic reviews suggest the importance of frequent interventions and regular follow-ups undertaken over an extended period of time, to promote enduring change.^{9,10} This has led other programmes to adopt a one-to-one support approach either in face-to-face sessions¹¹ or over the telephone over a year.¹² How the advice is given appears critical. There is strong evidence that patients do not want advice provided in a paternalistic style or if they are being 'told what to do'.¹³ The patient 'owning' the self-management process, and the diabetes educational programme supporting and enabling this, leads to an increased sense of control in their lives.¹⁴

Another way to conceptualize the necessary knowledge, skills and their reflective application for effective behavioural change is to explore self-care through the lens of health literacy. As Zarcadoolas *et al.*¹⁵ (pp. 196–197) helpfully outlines, health literacy represents '...the wide range of skills and competencies that people develop over time to seek out, comprehend, evaluate and use health information ... to make informed choices'. Nutbeam¹⁶ argues that health literacy should be perceived as an asset that can be built up through education and support. His influential framework¹⁷ differentiates three levels of health literacy (functional, interactive and critical), each of which can be re-translated into a behavioural change situation. The functional level involves the person having sufficient basic knowledge and skills to at least adhere with professionals' advice; the interactive level involves the development and use of more advanced cognitive skills, leading to a more active patient role, in accessing and applying knowledge and skills to changing circumstances¹⁸; and, the critical level is yet more advanced, with the person critically analysing information and using it to exert greater personal control over their lifestyle and health-care decision making and, most broadly, to engage in provide advice to others and wider community advocacy.^{19,20} As Coulter and Ellins²¹ comment, health literacy is an essential empowerment strategy and one that by implication may enhance self-agency (that is, an individual's ability to make meaningful choices in structuring their life).^{22,23}

Health literacy needs to be perceived and understood as being 'context-specific' and 'context-driven'.^{24,25} A person may be highly health literate in one context and not in another.²¹ The potential for making choices and participating in health-care decision making also depends on a range of wider socio-economic and cultural circumstances, such as opportunities for formal schooling and education,²⁶ income and housing.²⁷ The ability to make choices over lifestyle changes (for example, diet) is conditioned within the family context and the person and family's social, cultural²⁸ and economic situation, including access to and affordability of appro-

priate foodstuffs. Moreover, health (self-) care, decision making may involve a differential power relationship within the health-care encounter, with the potentially disempowered patient trying to come to terms with and/or cope with their illness.^{3,29} It thus becomes critical that initiatives for behavioural change pay heed to this context, both to initiate any behavioural change and to optimize possibilities for sustained change. Thus, by implication, whether or not a person who would be described as critically health literate (for a particular condition or ability to navigate the health system) and becomes more involved in wider health advocacy,²⁰ or even in giving advice to others (for example, through the UK NHS expert patient programme²³) is likely to vary, for example, in relation to their own wishes (regarding how much 'control' and involvement they want), social demographics and socio-economic circumstances.

Against this background, this paper examines changes in the depth and detail of diabetes-related knowledge and confidence which occurred with a group of patients with type 2 diabetes, who received an education and support intervention over a period of 3 years. Particular attention centres on changes in the form of advice-giving and advice-seeking, patient understanding and awareness, and advice uptake, all situated within a developing relationship between the patient and care provider. The paper aims to add to debates over the sustainability of the changes in knowledge and confidence that may occur within an on-going, behavioural change intervention and the potential to enhance health literacy among patients with a chronic illness.

Methods

The data are drawn from follow-up of participants originally recruited within a 1-year randomized controlled trial (RCT) evaluation of a proactive, call centre treatment support (PACCTS) intervention, whose primary aim was to improve physiological outcomes for persons with type 2 diabetes. Participants predominantly

lived in a highly deprived city location. The evaluation demonstrated significant improvements in glycaemic (blood sugar) control¹² and the acceptability of the PACCTS approach.³⁰ Patients within the RCT's intervention group were followed up for a further 2 years, while they continued to receive the PACCTS programme, which was then adopted into practice in a modified form.

The original RCT, reported previously,¹² recruited 591 patients who were randomly assigned in a 2 : 1 ratio to the intervention and control group. At the end of the trial, 319 remained in the intervention group and all were invited, and agreed, to continue to receive the PACCTS intervention and to take part in a follow-up, observational study. Ethical approval for the study was obtained from the local Research Ethics Committee. All patients gave written, informed consent.

The intervention

The PACCTS intervention incorporated several behavioural change theories, including patient-centred care⁶ and motivational interviewing.¹ Its initial focus lay on increasing patient knowledge and understanding of diabetes and individual self-management elements (monitor HbA_{1c}, diet, exercise and medication adherence) and then onto a focus on more general self-care to enable and sustain levels of control. The intervention was delivered by two non-medically trained tele-carers, supported by a diabetes specialist nurse (herself supervised by the consulting physician).

At prescribed intervals in a frequency inversely proportional to their level of blood glucose control (Box 1), proactive calls were made to patients by the same tele-carer. Each proactive call was scheduled for 20 min; patients could also contact the tele-carers on their own volition. The tele-carers used a structured questioning approach, supported by a protocol- and computer-based script, asking medical management and lifestyle choices. The software acted as a prompt for the tele-carers and as a device to log information such as glucose levels and pre-

Box 1 The PACCTS tele-care stepped call approach

Patients received calls, scheduled for 20 min, at a pre-arranged date and time, in relation to their level of blood glucose control:

Those with 'poor' control (HbA1c more than 9%) receive 1 proactive call per month

Those with 'moderate' control (HbA1c 7.1–9%) receive 1 proactive call every 7 weeks

Those with 'good' control (HbA1c 7% or less) receive 1 proactive call every 3 months

Interim follow-up calls are arranged if required. Following referral from the tele-carers, calls are made by the supervisory diabetes specialist nurse for urgent issues (for example, unexplained hypoglycaemia) or for routine supplementary counselling and medication change.

scribed/or negotiated lifestyle changes ready to follow-up at the next call. As the patients became more confident and familiar with the format of the calls, they were encouraged to identify their own needs making the calls more patient-centred.³¹

Data collection

Data were collected in two ways. Firstly, a purposely designed, postal questionnaire was administered to participants at the beginning of the observational study and 2 years later. The instrument asked about the acceptability of different aspects of the call centre (a set of 20 statements each scored on a five-point scale) and two open-ended questions, asking about changes made as a result of the advice and support provided and perceptions of control. Building on the emerging findings, this questionnaire was slightly modified for the 2-year follow-up, to contain four open-ended questions, covering the areas of the 'three most important' things about the treatment support centre, the relationship with the tele-carers, feelings of control and reasons to recommend PACCTS to others. The questionnaire also included the eight-item Diabetes Empowerment Scale-Short Form (DES-SF)³² and two 'confidence' statements (all scored on a five-point scale, with an extra 'don't know' box). Alongside, background data on age, gender and level of glycaemic control (HbA1c status) were obtained from PACCTS records.

The second source was in-depth interviews with a theoretically selected sample of 25 patients from four groups according to their pre- and post-RCT HbA1c results: those whose control remained either 'good' (HbA1c ≤ 7) or 'poor' (HbA1c > 9) ($n = 13$) and those whose control improved or deteriorated ($n = 12$), with equal numbers of men and women in each group as far as possible. These patients were re-interviewed after 2 years. The interviews explored what and how the participants had learned to make decisions about self-care, which elements of the intervention were helpful and which they would like to change. The interviews took place either at the University (travel expenses were paid) or in the patient's own home and were tape-recorded (with the informants' permission) and subsequently transcribed verbatim.

Data analysis

Quantitative data were analysed using SPSS for Windows. Analysis of variance was used to assess differences between groups, and Spearman's rho for correlations. The open-ended questions were grouped into five thematic areas drawing on behavioural change literature using the approach of directed content analysis.³³ For example, comments were separated to differentiate information provision aimed at raising awareness and enhancing knowledge, and advice-giving to provide support and to promote self-efficacy, which itself involves the person recognising, owning and internalizing the need for and adoption of specific self-care behaviours.^{34,35} Information provision was further divided to distinguish general from specific self-care behaviours. Drawing on the in-depth interviews, extracts from five participants were selected to illustrate the diversity of levels of control of blood sugar levels and changes in health literacy.

Findings

Participant characteristics

A total of 156 participants replied to both the baseline and the 2-year follow-up questionnaire.

Table 1 Levels of empowerment by end of follow-up, HbA1c status

	End HbA1c status					
	≤0.7 ('Good')		> 0.7–0.9 ('Moderate')		> 0.9 ('Poor')	
	Mean	95% CI	Mean	95% CI	Mean	95% CI
DES-SF	4.41	4.28–4.56	4.17	4.05–4.29	4.29	3.67–4.91
N	39		65		6	
ANOVA	$F_{2,107} = 1.54, P < 0.05$					
	Post-hoc, mean difference comparison: ≤7 vs. >7 to 9, $P = 0.033$					

Taking into account loss for follow-up ($n = 47$) over the 2-year study, owing to reasons such as moving out of the area, further serious illness, relative's illness or loss of contact, or patient death, this represents a response rate of 57% ($n = 272$, of the original 319 who agreed to take part in the study). Participants had a median age of 67 years, had had diabetes for a median of 6½ years and around two-fifths were women. There was no difference in age, gender or the length of time participants had had diabetes between responders and non-responders. Of the 25 persons interviewed at baseline, 16 were available for interview within the 2-week data collection time period.

Sustainability: knowledge, confidence and empowerment

At 2-year follow-up, nearly all participants continued to express strong agreement that they had taken on board the advice given by the tele-carers (99%), felt 'more knowledgeable' about their diabetes (97%) and were 'more in control' of it now (96%). Over 90% also expressed confidence in keeping their blood sugars within the desired range and controlling their diabetes so as not to interfere with their lifestyle. Scores on the DES-SF showed high self-perceptions of empowerment (mean = 4.26; 95% CI: 4.17–4.33, max = 5). The DES-SF scores were highly correlated with the two 'confidence' statements ($r_s > 0.5, P < 0.001$) and the four statements rating well-being, action, knowledge and feelings of control ($r_s > 0.4, P < 0.001$). Those with 'moderate' control had statistically significantly different, lower mean levels of

empowerment than those with 'good' control (Table 1).

Relationship with the tele-carers

A total of 134 persons (86%) listed one or more ways that were important to them about their relationship with the tele-carers. Most mentioned was the area of 'friendliness' ('it is like talking to a friend', 'one-to-one', 'she knows you') and 'providing friendly advice' which was acceptably given ('don't rebuke') 'helpful' and 'putting at ease'. Allied to this was the tele-carer being encouraging in their advice-giving, reassuring and giving confidence. Participants used phrases such as 'listening carefully', allowing 'me to speak', 'being easy to talk to', 'non-judgemental' and 'being able to talk and ask questions'. The flexibility of the scheduling (time and date), the calls 'not being rushed', or 'you can call back' and their 'always having time for you' was also strongly valued, along with there 'always being someone there to advise.' All of these factors are central to the wider notion of patient-centred care, engaging the patient in decision making, and supporting and enhancing behavioural change.

Nature of the behavioural and health literacy changes

Participants' comments about the changes in lifestyle they made and perceptions of control changed over the study duration. At baseline, in their responses to the open-ended questions, patients spoke in terms of 'everything has been explained to me', 'changing my attitude', 'giving

the opportunity to ask questions or *seek advice* and it being *the little things that they have told me that have made the big difference*. Respondents pointed to enhanced self-knowledge and changes in attitudes and behaviour. In in-depth interviews, the specific areas of diet and exercise were commonly mentioned, along with the importance and timing of blood sugar monitoring and the interpretation of the readings. This is suggestive of the tele-carers' gradually providing sets of specific information to the patients over time, for them to consider, try out and apply, and thus enhancing their functional health literacy – adding to knowledge and understanding to provide a foundation for more informed lifestyle decision making.

At 2-year follow-up, responses had changed, being phrased more generally, rather than about specific behavioural changes, and suggestive of a more active role in their self-care. When asked in the questionnaire to list the three main ways in which PACCTS had helped them to manage their diabetes, comments demonstrating their internalization of specific self-care behaviours across the range of lifestyle factors were as commonly mentioned as the value of external support via contact with the tele-health-care advisor. Patients talked in terms of *regular checking* of blood glucose levels, self-management of diet, exercise and medication and a general understanding of their illness. Alongside, being better able to self-manage specific aspects of self-care (diet, bloods and, to a lesser extent, exercise) retained their importance. Further indications of enhanced enablement and self-agency were evident in participants' comments about being *more motivated* or *more confident about control*, *how to prevent complications* and *where to get help*. As more information was provided, the patients' experiential knowledge improved and their ability to make informed self-care decisions choices about specifics and lifestyle in general was enhanced. Such evidence illustrates features of interactive health literacy and self-agency, in their reflecting on how to care for themselves and applying their knowledge and skills.

The advice and support provided by the respondents further subdivided into *reinforcing*

(current levels of knowledge or behaviour), *sustaining* (maintaining levels of knowledge and control) and *transforming* (behaviour, knowledge and understanding). At baseline, transformers' comments were indicative of greater understanding in general (*understand the complexities*), in relation to blood sugar checking (*know I have to check my sugar levels every day*, *be more punctual with my test times*) and specific behaviours (*watch my diet*, *eat healthy foods* and *keep fit*) (Box 2). Some explicitly referred to the importance of external support (*someone calling regularly* and *help at the end of the phone*). Two years later, comments were more general and indicative of the individual taking control (*importance of looking after myself*, *personally take control*, *self-discipline* and *build a self-administered regime*) or having greater confidence to take control (*keener to take control* and *confidence to cope*). Knowledge was also wider and deeper (*importance of looking after myself*, *complete understanding of diabetes* and *understand my problems and weaknesses*). In contrast, the three patients whose HbA1c level moved from 'moderate' to 'good' over the study (patients Q, S and T, Box 3) illustrate a sustaining effect from the tele-care intervention, for example, from *understanding the nuances* to *(being) able to design a regimen I can follow* or *establishing a strict routine*. Their health literacy is yet more advanced, with the person critically analysing information and using it to exert greater personal control over life events. These patients contrast to patients X and Y, who had continuing poor control and where the intervention had seemingly only reinforced their knowledge. Both patients point to understanding (either already knowing or some increased depth being gained) and awareness, but neither applied this knowledge to any great effect.

In summary, three groups of participants can be identified:

- Those who have learned enough (to enable either maintained good control or to enhance their control) are more empowered and have translated this into practice and are confident about their ability to sustain such control.

Box 2 Transformed understanding and confidence building

Patient/control status	Baseline	2-year follow-up
Transforming		
A: G -> G	I understand the complexities of my diabetes more now.	Understanding of why I have become a diabetic. The importance of looking after myself, i.e. weight (loss of 2 stone)
B: G -> G	The help that I receive on the phone are (is) very mind pleasing.	I feel confident that I can keep my blood sugars level.... I feel more in control
C: M -> G	I have to take notice of what I'm told I didn't know so many of the 'signs' that things weren't as good as they could be	To realise that this is a progressive (illness) – condition, over which I must personally take control
D: M -> G	To eat healthy food and keep a check on my blood sugar, and try to keep fit, i.e. walking.	I cannot fool myself as I once did, if my blood sugar is up I know why, before I ... would not blame myself for eating the wrong food.
E: M -> G	Come to terms and understand what diabetes is.... At first I was upset and worried about diabetes	A complete understanding of diabetes. To be able to manage diabetes.
F: M -> G	Watch my diet and keep a check on my diabetes	I understand my problems and weaknesses more. I hope I can keep it up
G: M -> M	Improve my diet. Develop my exercise regime. Monitor and regulate food and alcohol intake.	The centre has helped me build up a self- administered regime of diet, exercise and blood/sugar monitoring.
H: M -> M	Good support. (But) I am still not sure about my diabetes	I definitely feel more in control and understand my diabetes and I can honestly say this is due to the help I have received from the call centre
I: P -> M	Kept me on my toes and not to become too complacent...more punctual with my test times	Self discipline. Knowing advice is only a phone call away. Feeling I'm doing something right after phone calls.

Key: G, good controller; M, in moderate control; P, in poor control.
 G -> G, remaining good controller; similarly, for M -> M (moderate) and P -> P (poor).
 G -> M, changing from good to moderate control, etc.
 P -> G, changing from poor to good (moderate) control, etc.

- Those who have enhanced knowledge but are either not as successful in implementation or insufficiently motivated, or lacking in confidence and would value on-going support.
- Those who are not able to maintain self-care in a sustained manner without external support.

Five illustrative cases

To explore the meaning and significance of the intervention to participants and changes in their ways of managing their diabetes, Boxes 4–8 present five extended case reports, built around extracts from the interview data. The five cases illustrate diversity in levels of blood sugar control, changes in health literacy and the impor-

tance of the tele-carer, patient relationship and bonding that occurred.

Boxes 4 and 5 summarize two cases illustrating movement from 'poor to good' control. For patient 1, who is being cared for by her husband since her stroke, indications of poor HbA1c control prior to the beginning of the study are apparent. The husband points to previous advice from a dietician, but there being '*no back-up if you got a problem*'. A concern with achieving control is implied. This contrasts dramatically with patient 2, a divorced man now with a new partner, who '*just sort of ignored it (his diabetes)*'.

At baseline, both patients talk about explicit changes in their mode of coping (knowledge, skills and competence). Patient 1 and her hus-

Box 3 Sustained or reinforcing knowledge and behaviour		
Patient/control status	Baseline	2-year follow-up
Sustaining		
Q: M -> G	Understand the nuances of the changes this has brought to my lifestyle and enabled me to cope with them.	Able to design a regimen I can follow if I'm going on a long journey thro' time zones (i.e. to Oz).
S: M -> G	Take on board the do's and don'ts about my diabetes, at the present time I am in control with my diabetes, and rarely need help.	Never been in control I very soon was put in contact with the right person that was there for me at all time, and I am now in full control, and have done very well.
T: M -> G	Know what is acceptable when checking my sugar levels ... what foods to avoid and what can be allowed as a treat. Also when to worry and ... not about meter readings.	They have made me understand more about the safe/correct blood sugar levels at each time of the day, also with dietary advice.
U: M -> M	If I was on my own I would be saying 'what the hell' a mars bar's not going to hurt me.	Not wanting to let then down I have established a strict routine over the years.
V: M -> M	Helps me to manage my diet better... and keep a good check on my sugar levels better.	Helped me to control diet and sugar levels... more confidence in control of my diabetes and knowledge.
Reinforcing		
X: P -> P	Understand how important healthy eating and exercise is.	I have always been aware of the control of my diabetes.
Y: P -> P	I now feel that (a) (I) have a clearer understanding of my diabetes; (b) am more up to date on modern treatment; (c) am more flexible in what I can eat.	I have developed a broader understanding of my diabetes, am able to assess how physical activity will affect the amount of insulin I require and adjust it accordingly.
<p>Key: G, good controller; M, in moderate control; P, in poor control. G -> G, remaining good controller; similarly, for M -> M (moderate) and P -> P (poor). G -> M, changing from good to moderate control, etc. P -> G, changing from poor to good (moderate) control, etc.</p>		

band mention increased awareness of some of the fundamentals (diet and the importance not just of quantities but also carbohydrates; blood checking), implementing this knowledge (regular blood checking and *'keeping it (sugar levels) right'*) and expressed greater confidence. This is indicative of both enhanced functional health literacy (raised awareness and adhering to advice) and movement onto a more active role illustrative of interactive health literacy (confidence in implementation, recognizing the significance of information and developing skills). Patient 2 is similar. Beginning with minimal knowledge and minimal engagement with his condition, he is developing an understanding of what *'normal'* is and wants to achieve that normality. When he does not fully understand the advice given, he re-contacts the call centre. As his knowledge and skill levels continue to be built, he is becoming more confident.

Two years later, both have yet deeper knowledge and are exerting greater control of their own care, a core feature of critical health literacy. A shift to critically assessing and using developed and self-generalized knowledge and skills is apparent. Patient 1 and husband express increased confidence, linked to deeper understanding and greater competence about making behavioural changes. A key component is to understand not just *'what you are doing ... (but) why you are doing' it*. They are translating their awareness and increased knowledge about diet into ways to *'compensate'* for a reduction in one element by an increase in another, more beneficial element. A wider familial impact is also noted, with changes in their lifestyle *'rubbing off'* on their daughter and her family. Patient 2 expresses an even greater impact: *'I have never looked back since.... I am feeling good and three years on my overall health has improved.'* His

Box 4 Patient 1: 'Poor-Good'

Case history

A 53-year-old, married woman, who has had diabetes for 11 years on entry to the study and had a stroke prior to this (*I haven't come out physically from this, she uses a wheelchair*). Her husband looks after her and together they talk to the tele-carers (*I have to sort the food out and the insulin... (But) there was no back-up if you got a problem*). Her blood glucose control was 'up and down': *but it was 14. Something then your HBA1C, so we had come down to 10.7 when the PACCTS started but since you've been on there your highest has been 6.7*. Their expectations were minimal: *just see how it goes, you know what it does*

Perspective at baseline

I think it makes you more aware of what I'm giving (my wife) to eat. Not only what the food she eats but the quantity. It also increased awareness of the importance of the blood monitoring: you've got to do the blood, you want the blood to be right. I think it makes a big difference and I think you feel better in yourself knowing that the blood is right. Once you really get into it it's like a challenge to keep it right. They felt a lot more confident. Before PACCTS, they had received confusing dietary advice (from a dietician); (PACCTS) explained more about why you've got to have your carbohydrates. From the husband-as-carer perspective, as far as I'm concerned, not being diabetic but looking after a diabetic, it's made a big difference to me. I understand more about what diabetes is and I understand more about what I've got to do.

Perspective at 2-year follow-up

The most positive thing about receiving the care was *confidence in what you are doing and why you... It is what you are doing and why you are doing it. Not just do this, it's do this because it will do this. And it's not just the advice, it's the education factor of it as well*. The contact has also had a wider family impact: *I think it's rubbed off more on the daughter hasn't it? I mean she is married but her style of cooking now is more like ours, they are eating a lot more vegetables and everything, they don't seem to cook processed food, it's nearly all fresh*. The call centre has *more than met them (our expectations)*.

Changes

Their understanding and knowledge have been enhanced. Before, *I mean I didn't understand it all. But the tele-carers started explaining whereas even you haven't had, it hadn't been explained to you properly... I think we've changed our lifestyle, yeah... What has changed it is following their advice*. They have made a lot of changes, for example, over the timing and quantity of insulin and diet (more fruit and vegetables). *It's like the quantities of still having your carbohydrates but reducing them slightly and maybe increasing the vegetables to compensate for it, cutting down on red meat, eating more poultry which you know, that's been I think the main thing*.

Sustainability

I think we'll be able to maintain it (the control) but we wouldn't be as comfortable.

The relationship

As the months went by it got more, although they were ringing up for the results and seeing how things were going, it was more like a friendship rather than just a call you know to see how you were going on.

skills have developed (he talks in terms of 'a few big changes and lots of little ones'); there is a slow, but on-going, building of competence based on a trial and error approach to learning; he understands the consequences of not managing his diabetes and can evaluate and make decisions competently. He is now also able to tell his employer about his condition and, with the support of the tele-carer, his new partner. For both patients, features of critical health literacy, in particular, their becoming more 'empowered', is associated with indicative confidence about an ability to sustain such changes, when the tele-carer support is withdrawn, and an ability to

share the advice they had received on a healthier lifestyle with others (patient 1) or to talk about their condition (patient 2).

Patients 3 and 4, moving from 'good' to 'poor' control, contrast to the two 'poor to good' cases and to one another (Boxes 6 and 7). Patient 3's expectation of the intervention was divergent to its aim; he thought 'somebody would be coming here (to his home) to see how I was going on.' Patient 4, 'up and down' in terms of control prior to the study, is in a similar position as patient 2 ('I hadn't taken it seriously at all'). His expectation was that the intervention would provide him with 'a deeper understanding of diabetes.'

Box 5 Patient 2: 'Poor-Good'

Case history

A 50-year old, divorced man who on entry to the study had had diabetes for 8 years (*I just sort of ignored it. I didn't think there was anything wrong with me*). I was always a social animal and played a lot of football. After training I had a drink. At weekends I had a drink. Then I went through a divorce and I had more to drink. I was living the lifestyle that I shouldn't have done. Then I settled down. I kept getting ill. I just used to go to the GP or the nurse. They used to say, 'take the tablets'. She never used to say, 'You should be doing this' or 'You shouldn't be doing that' so I just carried on. His expectations were few: *I didn't expect really anything. I thought it was a bit of a chat*.

Perspective at baseline

He received excellent advice: *some of it has gone over my head sometimes, but I come o the phone and I think, 'Crikey what has she said!' ... I've phoned back and said 'sorry I've missed that one,' or 'what do I do?' It has helped in bringing you into line with normality*, for example, in relation to blood sugar levels and control in general with beneficial consequences for his social life. *It's been a struggle but I feel as though I'm getting there*. He is *more relaxed, totally relaxed about doing it now (monitoring and maintaining control of my diabetes)*. The advice has increased his confidence and *it's a little bit of a comfort zone*. In summary, *I'm willing to do anything to help myself to get back (to normality)*.

Perspective at 2-year follow-up

I was invited onto the study – I have never looked back since. I don't think I would be here if I had carried on the way I was.... Within 12 months, I was down to low numbers and now, I am in the 7s. I have cut the drinking down by 70%. I am a little bit healthier.... Three years on I'm still keeping the bloods in check.... I am feeling good and three years on my overall health has improved. The information, changing over time, *has improved me and I think it is invaluable. The call centre has met all my expectations even gone above them....*

Changes

I only used to take my blood sugars before when I felt like it (which wasn't very often). I didn't really bother but I know that taking them more regularly has helped. At one time, I took four per day but now I just do them twice. He also eats regularly (*which is pretty difficult when you do shift work*) and cut down on his drinking. *Just basic lifestyle changes and I exercise a little bit more. Overall, there were a few big changes and a lot of little ones but it seems to have come together. I sometimes didn't want to say what I had eaten but it did me good*. Before PACCTS, *I never told anyone about the diabetes*. Since then, *I started to sort myself out and I also talked to the managers at work Being able to talk about my condition has helped me to cope....* The tele-carer has also spoken to his girlfriend (*it has made her more aware of what might happen*).

Sustainability

Yes, it is going to be hard but you will just have to get on with it.

The relationship

It is a friendly voice. It is positive. Even if you have done something wrong, they don't tell you off. They will help you. They will advise you. They will encourage you.

At baseline, patient 3 expresses frustration at the seeming lack of new information to help his control while patient 4 points to increased awareness. Patient 3 indicates his '*knowing it already*', awareness of hypos and how to cope and avoid them (but not seemingly implemented). He is aware that he had '*gone a little bit off*' (poorer control), but '*I can't explain it to you really*'. Having the knowledge is not sufficient to enable its implementation; the mismatch of expectations may also be a confounding factor. In contrast, patient 4 expresses increased awareness and knowledge (how to keep control, food intake, future complications). While blood

monitoring has made a difference (*'it does help give me more interest in myself'*), he is not describing skills development nor changes in competence. There are indications of a motivation to change, through his following through on blood monitoring, albeit at a level of '*(I) at least feel that I'm doing what I should be*.'

Two years later, neither patient is in control of their diabetes. Patient 3 continues to express his irritation at the calls (*'always ask me the same questions...'*); he wanted something different, but what was unclear. At the same time, his knowledge has improved (*'I know a lot now'*), but there has been little change in his diet (save

Box 6 Patient 3: 'Good-Poor'

Case history

A 65-year-old, married man who on entry to the study had had diabetes for 15 years. *Everything was alright, everything was fine and then I found out this ...but I wasn't on tablets then, I did it by diet and after a few years I had to go onto tablets.* His expectations were, *well actually I thought there would be somebody coming here to see how I was going on.*

Perspective at baseline

He indicated that he knew already about managing his diet, exercise and blood sugar levels. *No disrespect but I already knew that, I already knew from going to the doctors and having my check-ups at the doctors.* He has a number of hypos, but seems to be accepting of them and find ways to cope with them. *It was usually that I have something to eat every three hours or something like that, but I felt a little bit...so it was a case of a couple pieces of chocolate.* He has noticed that *if I don't eat, if I don't have anything to eat in four or five hours, ... I go off, I feel weak ... But I've found now that if I have a drink of coke and I can lie back in my chair for a five minutes, five or ten minutes I come back up.* Knowing that his control is not so good, he comments: *I know what to do... but sometimes I have gone a little bit off, you know, I can't explain it to you really.*

Perspective at 2-year follow-up

He seems to have found the calls somewhat irritating: *they always ask me the same question, 'are you eating say this, this?' It's always the same.* But, he remarked, *if I'd had diabetes for a year I could have understood it but this is fifteen years, well, three years of this now and I know what they are going to say.* He feels that he has his diabetes under control. He watches what he eats (*me and my wife*). His knowledge about diabetes has improved: *I know a lot nowI've learnt how to treat it, what to do and not to do. Yeah. What I can eat, I never touch sugar now.*

Changes

He has *not really* changed the way he eats, except in relation to the amount of sugar: *I used to eat a lot of cake and I never touch cake now. ... If I have a biscuit, it's a plain biscuit.* He indicates the tele-carer has *enlightened me. So, it's been small changes rather than an overall, massive change if you like? Small changes. And, I know what to do now, I know what to do.* He appears confident about controlling his diabetes (*yeah, I am....I've had very good tips*). *I know what to do. I know the do's and the don'ts.*

Sustainability

Oh I've no problem, I know what to do.

The relationship

If I needed (the tele-carer) for a specific thing I could phone her... The best thing about the call centre is *knowing they are there.... peace of mind....advice.*

cutting the amount of sugar). He appears confident about controlling his diabetes, indicating that *'I know what to do. I know the do's and the don'ts.'* Such awareness has however not been translated into greater control. There is a seeming disparity between his beliefs, attitudes and preferences¹⁹ and his knowledge, leading to a lack of implementation. This is evident explicitly when asked about how he will manage when the intervention ceases: *'oh I've no problem, I know what to do.'* In health literacy terms, while his knowledge has been enhanced at a functional level, he does not seem to have internalized and taken ownership of the importance of modifying his behaviour to enable better control.

In contrast, patient 4 points to his *'starting to take it (my diabetes) more seriously'* and his

diabetes being *'more under control... (but) I find it difficult.'* He is motivated and interprets and evaluates his blood sugar readings, understands the need to do something about them and recognizes that he cannot just rely on the drug medication: *'I just have to get it back into control.'* While his control has not increased, he demonstrates enhanced functional and perhaps interactive health literacy through expressions of a sense of ownership of the condition and his role in its management; *'I contribute to the care myself rather than feeling that I am on the edge of it.'* In comparison with patients 1 and 2, patient 4 is not as far along the learning curve or as motivated and thus exhibits more limited self-agency; his knowledge and skills have improved, but he is not yet competent in their implementation. This is

Box 7 Patient 4: 'Poor-Poor'

Case history

A 53-year-old, married man who on entry to the study had had diabetes for 13 years (*I hadn't taken it seriously at all.*) He did not know what to expect from PACCTS. *Obviously I thought it might be of some benefit to myself to, you know, a greater understanding of diabetes.*

Perspective at baseline

The calls have *made me more aware of what I need to do to keep control and also it has made me more aware of the implications in the future.* He has learned *even things like food intake, what to eat, what not to eat.* He does not let diabetes interfere too much with lifestyle. The blood monitoring has made a difference: *it does help give me more interest in myself to see whether I'm doing well so now I'm doing like four a day now. And, I want to do it for XXX (the tele-carer).* Doing the blood sugar levels checks is not a *pressure as such I see it as I want to do it and at least feel that I'm doing what I should be.*

Perspective at 2-year follow-up

He expresses awareness about his level of control: *my control hasn't been desperately exciting.* While at the beginning of the study, it was *up and down, not regular at all.* However, *this is now more under control since I started the study.... I find it difficult ...but I think I do quite well really.* He knows more about diabetes now: *I am more aware in a way that is helpful rather than in a way that makes you frightened to do things.* The most positive aspect has been *definitely awareness and education.* PACCTS has also had an impact on his wider family. *I didn't even tell anybody that I was diabetic apart from my wife and close family because I thought it would go away – which of course, it won't. Well, the wife eats what I eat and the kids are aware of the implications of diabetes...* Reflecting on his initial expectations, he comments: *I felt that they were trying to help me and I was doing nothing to help myself to help them. So that is why I then started to take it more seriously. I had, shall we say, more respect for the readings and I started trying to do what they were asking me to do.*

Changes

He has changed his diet; *it still comes as a surprise when someone asks if you are eating wholemeal bread.* The advice has helped him in relation to *just even small things* (what to do if his reading is too low or too high) and to feel more motivated now to keep his diet under control (*it just makes me feel that I just have to get it back under control*). He started to take his diabetes more seriously, *more or less when these calls started.... you still sort of tend to rely on the medication but somebody explained that you need to control it yourself if you can and let the medication do the rest rather than the other way round.* He expresses greater control and a sense of empowerment; *I contribute to the care myself rather than feeling that I am on the edge of it.*

Sustainability

He is not confident about his ability to control his diabetes if the calls were to cease: *I would, but for how long?*

The relationship

They know me.... It is more of a discussion with two parties rather than being told, 'You need to do this and that and then come back and see me in 6 months.'

also expressed in his lack of confidence about his ability to control his diabetes once the calls cease: *'I would, but for how long?'*

The final case study relates to a continuing 'good' controller (Box 8). Patient 5 looks forward to the intervention, seeing it as providing *'just a bit extra.'* His proactive approach is noticeable, taking the initiative to talk to the doctor and to find courses on diabetes. Such action is consistent with the empowerment feature of critical health literacy and a sense of self-agency. At baseline, he reaffirms his level of control, his approach to blood monitoring

(*'I just check it for my own reasons'*) and knowledge about how to maintain control through what he eats. Two years later, he indicates that he has learned *'quite a bit ... about trying different sorts of foods'* and he has achieved a goal of losing some weight. He is *'more aware of the future and to keep looking after myself.'* At the same time, he has found it *'a boost ... knowing I am okay'* and helpful in *'pass(ing) on things to my children and grandchildren because they maybe at risk.'* In terms of health literacy, he began and remained in the position of taking control for his self-care,

Box 8 Patient 5: 'Good-Good'

Case history

A 70-year-old, recently widowed man, who on entry to the study had had diabetes for 18 years. His son and daughter live nearby. *When I first became diabetic...I read an article in the paper so I went up to see the doctor about it.... I rang the hospital and found out that they did courses and we went down and learnt all about diabetes So I was being very well looked after you know before the calls. So this (PACCTS) was just a bit extra, kind of. He thought that the PACCTS would be very good.*

Perspective at baseline

They phone me every three months and I have to tell them all my readings for a couple of weeks and then they say, 'brilliant YYY, see you in another three months'. He was also was in control, and PACCTS has reinforced this. I know my own diet and I know what to do... I know when to eat, what to eat, how to eat, go for a walk round.

I'm controlling my own diet. In terms of blood glucose monitoring, I check it everyday, it doesn't matter whether they ring or not, you know. I just check it for me own reasons.

Perspective at 2-year follow-up

I've been pretty steady I've not really had any ups and downs. My sugars are more or less the same, stable. But it's still been useful I've learnt quite a bit you know- they have talked to me about trying different things different foods etc. I've picked things up along the way. I am healthy but it's reassuring to be able to ask and for them to help you stay that way. It's like an extra eye that's there looking after you along the way – I enjoy the chats...It has met his expectations: they have developed me with my diabetes so that I can manage.

The process

Yes, it's... you are kind of being checked quite frequently you know. So yes, I think it's very good. My things been my weight they have helped me to loose a bit of weight- more from giving me options eating more fruit tweaking with what I have got really rather than anything dramatic. But it's a boost for me knowing I'm okay and I can pass on things to my children and grandchildren because they maybe at risk....

Changes

Well, you see, I've always done alright as it was....well when you've been like this for such a long time you know what not to have, how much to have and how much not to have and... And it's not made any difference with the family because well we all have the same and they can have a bit more if they want it. So you know it's... not made a big difference but I have changed things and it's made me more aware of the future and to keep looking after myself.

Sustainability

I had an idea what my diabetes was but I didn't know that much about my blood sugars. Now it just comes automatically and I know what to do.

The relationship

Yes it is somebody, you kind of look forward to it, here is somebody coming to check on me and she'll find there is nothing wrong. Well it's there in the background isn't it for you. You know it's there behind you so all you've got to do is ring.

while gaining additional knowledge. Coupled with his positive and proactive approach, he expresses his confidence in being able to sustain his control; *'it just comes automatically and I know what to do.'*

In summary, these five cases illustrate both a change in the nature of the experienced behavioural changes (from the specific to the more general) and potential movement along a health literacy continuum.²⁹ Such changes took place within a nurtured and developed relationship with the tele-carer. This bonding supported and contributed to a growing con-

fidence in the patients about how to manage their diabetes, experimenting and implementing changes.

Discussion

The findings demonstrate not only changes in the depth and detail of diabetes-related knowledge and confidence but also enhanced competence in translating knowledge into everyday self-care. Changes in health literacy within this individually targeted intervention were evident in the shift from specific to more general

knowledge, lesser reliance on external (tele-carer) support, greater self-responsibility and enhanced confidence. A core feature of critical health literacy, their being enabled to exert greater control in their self-care decision making, was demonstrated. Whether the behavioural changes found in the current study are sustained over time following withdrawal of the on-going support¹¹ and any wider impact of their enhanced health literacy on other family members remain subjects for further research.

The findings can also be interpreted from the perspective of individual agency. Some participants' comments suggest they are becoming more active while others are building on the tele-carer support to extend their sense of agency. For many, there is evidence of a shift from 'adhering' to advice in a relatively passive manner (functional health literacy and limited self-agency) to identifying their own goals and/or internalizing and owning requisite disease-related control goals and exploring for themselves, with tele-carer support as necessary, how to achieve their goals. Enhanced self-agency can also be seen within comments about increased motivation and greater confidence in envisaging and trying out different self-care decisions, albeit potentially constrained by their own socio-economic circumstances, demographic profile and other ill-health or mobility restrictions. The way the intervention unfolded facilitated active self-care by facilitating patients' ability to act on behalf of goals that mattered to them, and thus enhance self-agency. As the relationship developed, the consultations became driven by the patients' self-expressed need for more detailed information. They felt increasingly able to disclose more and thus to receive individually tailored support.³⁶ Further research on the potential for self-agency is warranted and to contrast its expression by other persons with type 2 diabetes, in particular, younger people making choices about good control within the context of wanting to live 'as normal a life' as possible. In addition, while empowerment and self-efficacy in terms of individuals gaining skills and knowledge for self-care and decision making was core to the tele-care intervention, it would

be interesting to explore the effect on self-agency if the behavioural change intervention was even more centred on developing problem-solving skills in general.²³

From a behavioural change intervention perspective, it becomes critical to be able to target on-going support to those with greatest need. In practice, this would mean more resources are provided to those considered to be high risk and who seem unable to maintain self-care in a sustained manner without external support. A reduced level of support would be targeted at those who have gained knowledge but are either not as successful in implementation or insufficiently motivated or lacking in confidence. Those who have already learned enough to enable either maintained good control or to enhance their control have translated this into practice and are confident about their ability to sustain such control would need little or more limited support.

The findings of the study reinforce the importance of including a qualitative component in complex trials³⁷ to gain additional insight into how and why interventions produce specific outcomes and to identify those at greatest need who may need specific kinds of interventions. As Ockleford *et al.*³⁸ describe within the qualitative component of the DESMOND evaluation,⁸ patients may adopt a range of different 'diabetic identities', and thus different levels of engagement.

This research also adds to the body of knowledge on the acquisition of health literacy from the patient's perspective. The qualitative nature of the study provides insight into some potentially core processes that occur from knowledge gain through to motivation and confidence and onto behavioural changes. The findings should assist health literacy instrument designers in clarifying the content of domains that are of significance and meaningful to patients as they develop their knowledge, skills, confidence and motivation to make such changes.

Conclusion

Making and sustaining behavioural changes in diabetes are not unproblematic. Rather than

addressing possible knowledge 'deficits' in advice-giving, advice must be 'context-driven' and made relevant to the socio-economic context of participants.¹⁸ While participants were selected for this study on an external, objective clinical criterion (levels of blood sugar control), this both implies and was found to be linked to varying levels of prior knowledge and, most importantly, competence in its implementation. The intervention could be interpreted as operating at two levels: health literacy, enhancing knowledge, developing personal skills onto enabling self-control and self-agency; and social psychological, behavioural change, working on levels of motivation, empowerment, supportive problem-solving and support in general. Both approaches find reflection in the findings and provide powerful explanatory lenses to interrogate the data.

Translation of knowledge and willingness to change into successful and sustained self-care has to be carefully managed by the patient. Such management is likely to benefit, or indeed need, constructive feedback and external support. Alongside, and especially with the older age of the patient group in this study, the patient has to cope with their everyday life and other ill-health challenges that arise. What the implications might be for a future and younger generation of type 2 diabetes patients remains an interesting future question for research.

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Conflicts of interest

None.

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