

Case typologies, chronic illness and primary health care

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Case Typologies, Chronic Illness and Primary Health Care

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Summary

Rationale and aims and objectives

When assessing patients, clinicians use typologies developed through their idiosyncratic clinical experience. Our aim was to develop a typology, based on the patient's perspective and not specific to one illness, with the potential to enhance person-centred clinical follow up of those living with chronic illness.

Methods

We applied the qualitative comparative method to interview data from 37 people living with type 2 diabetes or with chronic back pain, recruited from UK General Practices. Informed by theory on time and complexity, analysis focused on the on-going adjustments made by individuals living with chronic illness (their dynamic) in current time. Health professionals (n=20) and people living with diabetes or living with back pain (n=14) refined and validated the typology in five focus groups.

Results

We identified the following types of dynamic: Past Reminders, Stuck and Struggling, Becalmed, and Submerged. Among interviewees who provided data at different time points, we found some transformed from one dynamic type to another.

Conclusion

This typology may aid personalization of treatment decisions and could be extended to other chronic illness. 5

Introduction

The purpose of this study was to develop a typology of patients living with chronic illness that is not tied to a particular disease or health care pathway. We focused on developing a typology for use in routine clinical follow up, particularly in primary health care. Historically, doctors have been trained to assess patients with acute symptoms for the purpose of making a diagnosis. However, the majority of primary care services delivered today centre around on-going management of patients with one or more established chronic illness. For doctors in primary care, a new approach to assessment and routine follow-up of these patients is needed. Follow up can be time consuming (1) and often involves the use of specified frameworks (2). However, patients dislike receiving standard advice (3) and expect individually tailored management (4, 5). In primary care, doctors and nurses are expected to provide high quality patient centered chronic disease management (1, 6-8). We suggest this task might be made easier if they had a research based typology to use. This article describes the development of such a typology.

We analyzed two sets of interview data, one collected from people living with type 2 diabetes and the other from people living with chronic back pain, conditions commonly managed in UK primary care. The data had been collected by FG, AL and JS during qualitative studies associated with clinical trials of complex interventions (9, 10). As we aimed to develop a typology that was not specific to one chronic illness we combined the datasets for analysis. As clinicians mostly see their patients for follow up when they are not at a crisis or transition point (11) we focused on just the current phase of chronic illness. This also avoided the danger of considering chronic illness as a one directional trajectory (12-15). Our analysis was influenced (16) by the work of Barbara Adam on time and complexity (2004; 2005a; 2005b) who argues that the whole of a person's experience, past, present and future is in some way expressed in how they are currently (17). Our earlier methodological research had investigated how to analyze interview data from people living with chronic illness in order to classify them (18). As in other studies (19-21) our research suggested the importance of focusing on the dynamic of living with chronic illness. We developed the following definition of current dynamic: the on-going process of adjustment when living with a chronic illness. This could include adjustment within or between the biological, psychological or social spheres of the life world (22) and that in some way was linked to their chronic illness. For each of our interviewees, we aimed to characterize their current dynamic of living with chronic illness and classify it.

Typologies of living with chronic illness

Qualitative research on the patient experience of living with chronic illness includes classic studies and reviews of illness narratives and the trajectory of illness (23-30). This body of research has been influential in alerting clinicians to the importance of understanding patients in terms of their biography and phase of illness. It has also provided typologies of illness narratives and trajectories to assist clinicians. For example, Anselm Strauss and Juliet Corbin suggested a model for use in chronic illness nursing, where the ill person, their care-givers and health professionals devise and revise an anticipated trajectory of illness (containing phases of stability, instability, crisis, comeback, deterioration and dying) which they then try to manage and shape (24).

Following the tradition of Corbin and Strauss, within specific disease domains, qualitative researchers have undertaken empirical work leading to the development of typologies of living with or managing the disease. This research, it is argued, provides insight into the experience of living with chronic disease that clinicians can use to improve their clinical practice. For example, research with people living with type 2 diabetes suggests three types of people: those who adapt their lives in an attempt to comply with their health professionals' recommendations, those who adapt how they manage their diabetes to suit how they lead their life, and those who have not found any sustained strategy for managing their diabetes (15, 31). Similarly, people living with

back pain have been classified as either believing that pain and activity are harmful or believing it is not harmful (32). Those with severe back pain have been classified as perceiving their pain as taking them over, or coming to terms with their pain (33). Meanwhile, researchers interested in clinical reasoning and decision making have demonstrated that clinicians use typologies (34) and that typologies are one of a number of ways they represent knowledge to assist them in the process of assessment and diagnosis (35).

Typologies and clinician patient interaction

Typologies have also been developed through qualitative research focused on interactions between patient and health professional, particularly in primary health care (36-40). May et al (41) analyzed interviews with UK general practitioners (GPs), and drew out a number of types of typologies which frame GP interactions with patients: types of patients, types of problems and types of options for solving the problems. They argue that the use of typologies does not suggest that a clinician is treating a patient only as a representative of a certain type instead of considering them as an individual and personalizing their health care (41, 42). For clinicians seeking to conduct a patient centered consultation (43-45), listening for and integrating the biomedical, psychological and social dimensions of illness as recounted by patients, amounts to considerable complexity. This large amount of complex information is reduced to a manageable level by defining a limited number of patterns and classifying individuals accordingly. Experienced practitioners use remembered patterns or types (46, 47) but these can vary in a highly idiosyncratic manner between clinicians (48) because they are based on individual clinical experience. We sought to develop an alternative to these idiosyncratic typologies, that is, a typology for chronic disease that is not disease specific and is based on the perspective of the patient rather than the clinician.

Methods

We analysed semi-structured interviews undertaken in the West Midlands of the United Kingdom between 2005 and 2009. In our first phase of analysis we aimed to develop a typology of the current dynamic of living with chronic illness. We analysed the interviews and held five focus groups with patients and health professionals with experience of diabetes or back pain to refine and validate the emerging typology. In the second phase of analysis we categorized each interview using the typology. The research team comprised three social science trained researchers (FG, AL and JB) of whom two were also Family Physicians/General Practitioners (FG and JB), two further academic Family Physicians (NDB and MP), a nurse with behavioral science training specializing in diabetes (JS) and a clinical trialist specializing in rehabilitation (SL), along with two members from each of two established research user groups (see acknowledgements). Ethics approval for the study was granted by Coventry Research Ethics Committee (reference number 08/H1210/27).

Recruitment for interviews

Recruitment was planned in conjunction with the relevant clinical trial (9, 10). Only those able to undertake an interview in English were included. Invitations were sent to potential participants by their general practitioner. Recruitment, data collection, transcription, anonymisation, and thematic analysis continued concurrently until thematic data saturation, for the purposes of the clinical trial, was reached.

For interviews with people living with back pain, two general practices, one urban and one rural were identified that had indicated an interest in participating in research but had not chosen to recruit patients to a clinical trial for back pain (10). The practices searched their records for adult patients who had consulted within the last month about back pain, where the pain had been present for longer than six weeks at the time of the consultation. Patients who had a diagnosis of serious back pathology such as spinal stenosis or metastases were excluded. Those participating

in an initial interview were invited for further interview 3-6 months, 12 months and 24 months later.

People living with type 2 diabetes were recruited for interview during a clinical trial of an educational intervention (9). Recruitment was from the disease registers of general practices recruiting to the clinical trial. The intervention aimed to improve self-efficacy of patients in managing their diabetes. Participating patients were adults and were not taking insulin. Sampling for interviews was stratified by age, gender and ethnic origin and aimed to recruit participants with a range of base-line self-efficacy scores as measured by the Diabetes Management Self-efficacy Scale (49) and equal numbers from each arm of the trial.

Interview process

The interviews with both those living with diabetes and with back pain explored the experience of living with the chronic illness. Initially, interviewees were asked to talk about their life in general to provide us with context, then to talk about living with their chronic illness including coping, self-management and treatment strategies and how the chronic illness impacts on their daily life. The original study designs were for single interviews with people living with diabetes and for follow up interviews with people living with back pain. Follow up interviews were similar but concentrated on current experience. Our approach to data collection considered the interviewees to be immersed in the world with time and context impacting on their experience (50).

Analysis: development of a typology of living with chronic illness

The interviews had been transcribed and anonymised prior to our analysis. Initial immersion in the data by FG and AL was followed by team analysis discussion. AL then extracted from each transcript all data referring to the participant's current phase of illness. Where the timeframe was unclear data was included in the extract. We did not impose a definition or boundary for the current phase in terms of calendar time (51), but were guided by whether or not the interview text indicated the interviewee was talking about the current phase. Twelve interview extracts were then selected at random for initial exploratory analysis by the team. Three interview extracts were read by each team member who then wrote a summary of the current dynamic for each extract. To limit the influence on data interpretation of the background of each team member, we allocated the same extract to two team members with different backgrounds and compared their summaries. At this stage of analysis we only used extracts from interviews with people living with back pain, as this gave us the advantage of being able to compare interview extracts from the same people at different times as well as comparing between people. When summarizing the current dynamic for each extract, some team members used metaphor: "Sense is that patient is on a long slippery downward slope". Others used more psychological language: "Fairly stable...can only be ill / in pain/ disabled for so long—elements of learning to live with it". One of the team members from a research user group included interaction with health care services: "Anxious about most things. Feels let down by the health service: a) waiting b) unresolved pain c) unclear about the care process. Feeling hopeless, maybe depressed". The summaries were collated and then reviewed and discussed by the team. Although the style of summaries varied, there was similarity in the tenor of the summaries of the same extract. When summaries of different extracts were compared some commonalities were identified. From this analysis we developed a prototype typology. AL and FG then comparatively examined further interview extracts including those from people living with diabetes to refine the typology.

Analysis: focus groups to refine and validate the typology

During the development of the typology FG and AL conducted five focus groups, one approximately every two months. Focus group participants were members of existing professional groups (physiotherapy (n=9), physiotherapy educators (n=5), general practice educators (n=6)) or patient support groups (diabetes (n=8) or chronic back pain (n=6)). One focus

group discussion was scheduled during one normal meeting for each of these groups. Each focus group was presented with the typology at its current stage of development, with each type illustrated with quotes from relevant interview extracts (diabetes extracts for people living with diabetes; back pain extracts for people living with back pain and physiotherapists; both for general practitioners). Group participants were asked to consider whether the different types were recognisable, and to discuss change over time in chronic illness. Focus group discussions were audio recorded and transcribed. Discussion about the typology and about change over time was extracted and summarised. This was used to inform further refinement of the typology into four relatively distinct types of current dynamic and to develop a description of the types.

Analysis: categorization of each interview using the typology

Two team members AL and FG independently classified each interview extract as being most like one type of dynamic. We compared classifications and discussed inconsistencies until agreement was reached.

Results

The study participants

Fifteen people living with back pain were recruited and completed interviews at base line. Three to six months later, of the 15 people recruited, 12 completed interviews, at 12 months 7 and at 24 months 6 completed interviews. Interviewees were aged 35-69 years; nine females and six males; all self-declared their ethnicity as White British; nine were working, four retired, one was a carer and one was not working due to ill health; duration of back pain ranged from 15 weeks to 35 years. Twenty two people living with diabetes were recruited for interview. These were aged 25-80; ten females and twelve males; self-declared ethnicity - fifteen White British, five Asian, two Irish; self-efficacy scores ranged from 47-150 (scale 0-150 with higher score representing greater self-efficacy).

Typology of the current dynamic of living with chronic illness

Four types of current dynamic were identified which we labeled as follows: Past Reminders, Stuck and Struggling, Becalmed, and Submerged. A definition of each type is provided below along with quotations from interviewees illustrative of each type. Interviewees are identified with a pseudonym that reflects their gender. For interviewees with back pain we specify whether the quotation was taken from an initial or follow-up interview.

Past Reminders. Definition: Sense of calm but very aware of the ever-present danger of a recurrence of past distress.

Eight of the 15 interviewees living with back pain were classified as experiencing this dynamic for at least one interview. Four of the eight interviewees were classified as Past Reminders at two different time points (see table 1). Interviewees talked about warning signs of a recurrence of back pain:

"It is completely manageable. I mean I haven't had to take painkillers or anything like that so it's not severe you know? I can feel it there and I suppose it's a little warning, isn't it. Be just careful."

[Monica - follow-up]

Interviewee's responded to the warning signs in various ways. Debra was cautiously optimistic about achieving a balance between pain and activities ". . . obviously much better than it was, isn't it? . . . I went to the ballet the other day and sat through the ballet although by the end of it, it was (sore)."

[Debra - initial]. In contrast Charles was very fearful of bringing back the earlier pain "[my back is] a ticking time bomb" [Charles - follow up].

From the 22 interviews with people living with diabetes, seven were classified as Past Reminders. Interviewees talked about memories of times in the past when they had found it difficult to live with and control their diabetes.

“Well like my naughty days . . . I remember I went to a birthday party and all of the men got together afterwards and they had a game of cards and I was drinking whisky . . . I was feeling physically sick three or four times throughout the night and I felt . . . I checked my sugar levels and, actually I’m not sure if it was that night, but it was 21 and I felt, I mean 21’s seriously high isn’t it?” [Damian]
(Damian is referring to blood glucose level measured in mmol/l.)

These memories influenced their current actions. For some, distressing memories motivated them to be more vigilant. However, others feared what might happen if they tried to reduce their blood sugar levels and accepted levels that were higher than ideal. Present stability was sometimes compared to past chaos. For example, Colin contrasted the variation in his blood sugar now compared to that in the past and was reassured that he was doing alright: “a slight variation on a daily basis but not a big variation”. [Colin].

INSERT TABLE 1 ABOUT HERE

Stuck and Struggling. Definition: A dynamic of floundering with a lot of activity. A desire is expressed to move on but with no sense of how to do so.

Ten of the 15 interviewees living with back pain were classified as experiencing this dynamic for at least one interview. Five of the 10 interviewees were classified as Stuck and Struggling at two different time points (see table 1). Some interviewees said they did not understand their condition or were unsure about what to do.

“I was frustrated because the exercises didn’t seem to be doing anything and she hadn’t told me how many times I should do them, how often and you know, they were just a series of exercises and “Do them”. But I said “Well, shall I do them every day or every week or every fifteen minutes?” and you know, I don’t know so I didn’t feel as well informed as I felt I ought to be.” [Ida - initial]

Others described being in limbo, unable to move on while they waited for something such as information, a diagnosis, or test results.

“Now what I’m told is, it is wear and tear and I’ve got to live with it and I’m not particularly happy with that diagnosis. Hopefully when the MRI scan is carried out then they’ll be able to see what if anything is actually wrong with the back . . . the sooner I can get it sorted one way or the other the better.” [Frank - initial]

Of the 22 interviewees with diabetes three were classified as Stuck and Struggling, describing a sense of chaos and an inability to achieve stable blood sugar levels. Peter talked about not “getting to grips” with his diabetes. Monica described an inability to prevent rapid changes in her blood sugar and her frustration with this:

“Life has changed a lot to be honest. I can’t do much of what I want to do, which is always worrying - am I too low or am I going too high and walking around. I love my walking. I walk two hours every day and then I go low and I think I’m going to be too low if I don’t have something to eat and then you build yourself back up again, but you have to keep building yourself down.” [Monica]

Elizabeth also described frustration:

"It's like I'm like a little hamster and I'm running round and round and sometimes I hit everything. Everything's working quite well and then one slight - like a cold or Christmas or anything - it could be anything and it knocks it all out of sync and I'm trying to get one thing sorted and something else goes downhill, and if it's the arthritis at times when I can't walk and I can't do much, then it's the diabetes that goes down. If I'm depressed and everything then it's the diabetes that suffers."
[Elizabeth]

Becalmed. Definition: Sense of calm, adjusting in small ways while living with chronic illness. No expectation of major change in the future is expressed.

Six of the 15 interviewees living with back pain were classified as experiencing this dynamic for at least one interview. Two of the 6 interviewees were classified as Becalmed at two different time points (see table 1). Interviewees had accepted having back pain for the rest of their lives, although with some fluctuation in the pain. "It comes and goes. It's there all of the time in a very gentle way." [Leonard - initial] For most of these people adjustment was based on their understanding of what caused their pain from which they developed coping strategies (e.g. medication, pillows, chiropractor visits).

I'm resisting painkillers but I've been doing lots of stretches and exercises and I really respect everything I do and I'm very careful. It doesn't really stop me from doing day-to-day stuff. I mean I can't do (physical education classes) and stuff that I used to with the children, so I tend to work in the swimming pool because there's no stress on my body in the pool so... Yes I've learnt to live with it and I've learned to sleep in the right positions. [Ann-follow-up]

Some expressed an underlying worry that getting older meant that their back pain or mobility might slowly get worse.

Of the 22 interviewees living with diabetes, 10 interviewees were classified as Becalmed. They expressed no expectation of major change in the near future although they worried about complications later in life. Many years of living with diabetes meant their management strategies had become routine. Change in their experience of their condition was very slow. Some were able to draw almost unthinkingly on simple routines or problem solving strategies to manage their diabetes.

We watch what we eat and when I'm buying food, you know, we've got used to what we can eat. We use a lot of fresh vegetables and we grow them in our own garden . . . I'll do my own test first thing in the morning and it doesn't worry me, you know? I mean, all right if it comes out a bit high I'll say well what did I eat yesterday that I don't normally eat? Perhaps I've had a sweet or a piece of chocolate, which is very, very rare and I just think, well I'll check it the next morning. [Brenda]

For others, the state of being Becalmed was only achieved by constantly working at managing their diabetes. 'Hopefully, I can maintain myself, exercise more, lose weight' [Teresa]. However, there was no sense of floundering as there was for those classified as Stuck and Struggling.

Submerged. Definition: Immersed in and overwhelmed by the chronic illness. There is a sense in which time almost stands still and there is a strong feeling of loss. There is no description of adjustment or any expectation of change.

Three of the 15 interviewees living with back pain were classified as experiencing this dynamic for one interview each (see table 1). These interviewees described an unhappy state, where the pain dominated their lives.

"I keep gritting my teeth but as I say, I don't do much anyway but I keep gritting my teeth and doing what I can. My gardening is my main occupation now . . . I'll go and do a job where three days I'll think about it and one day doing it, you know - it's not very good." [Neil - initial]

Of the 22 interviewees with diabetes 2 were classified as submerged. They described being resigned to a reduced life that they resented particularly where food was linked to pleasant past experiences. Peter expressed regret about what he was no longer able to eat: "I was a coffee and chocolate man" [Peter]. Adrian also expressed a strong feeling of loss:

"I hate it. I absolutely hate it. I can't really describe it because it changes your life around completely . . . you can't do this, you can't do that, you can't have that. You know, it does change your life completely . . . you've got to cope with it or you don't survive as they might say – a severe headache." [Adrian]

For interviewees of this type, time almost stood still. These interviewees did not describe the adjustment processes described by those classified as Becalmed. Unlike the interviewees classified as Stuck and Struggling, there was a sense of no activity.

Focus groups

Discussion in the focus groups contributed to the refinement of the typology. During the focus groups with members of diabetes or back pain support groups, participants recognized the types of dynamic of living with back pain or diabetes and offered comments and stories about similar experiences:

'She (type: Past Reminders; example: Debra) has made progress where she has actually sat through something.... I stopped going out with my friends for a meal or to the pictures initially because I couldn't sit that long.... So what I did was I practiced sitting for a bit longer and playing around with medication... It's a case of doing them but just doing them differently. [Focus group of people with back pain]

She (type: Stuck and Struggling; example: Elizabeth) has asthma and arthritis and when you're on so much medication that is when you get confused about what you ought to take. I was ill with a bug and didn't know what to do about my diabetic tablets. [Focus group of people with diabetes]

Professional participants described patients they had encountered that were similar to those in the typology: 'she (type: Stuck and Struggling; example Elizabeth) is certainly a real patient. Often you see simulated patients being made, which aren't necessarily that realistic.' [Focus group of general practice educators].

We made the following refinements to the typology. Our prototype typology had included 'Fearful Waiting' and 'Cautious Optimism', however through discussion in the focus group we clarified that both types were fearful of a return of distress although people of the latter type were more hopeful than the former. These types were combined as Past Reminders. Discussion of the type 'In Limbo and Deteriorating' in our prototype, resulted in changing the description to 'Submerged'. This distinguished it from 'In Limbo and Struggling', which after discussion we changed to 'Stuck and Struggling'. The professional focus group participants talked about how they responded to patients of each type. For example, the physiotherapy participants discussed the

Becalmed type as follows: ‘he is resigned that this is how it is for life(we) show them that there are some improvements’. The GP Educators discussed patients moving between phases, but emphasized that this was usually not in any particular order. They found the vignettes useful for helping them realize how the patient might be thinking. However, for making clinical management decisions they wanted evidence that for particular types of patient certain treatment approaches would be more successful.

Change of classification over time for individuals living with back pain

For 12 of the 15 interviewees with back pain we had more than one interview. All of these 12 interviewees transformed from one type to another at some point (see table 1). For example, Charles was classified as Past Reminders at base line and six months. He was fearful of more pain and over the six months becoming more worried and anxious. However, by 12 months he described every day as a fairly good day and he was resigned to being careful and calm about letting it settle, so he was classified as Becalmed. Ann was classified as Past Reminders at baseline but by six months she had changed to a more resigned state, with no sense of possible change and so was classified as Becalmed. She said: “I’ve learnt to live with it... my life will never be the same”. By 12 months, after making major changes to her work and leisure activities, she had less back pain but was aware of the possibility of the pain returning saying: “I’m very careful”, so she was classified as Past Reminders. We use the word transformed as the interviews indicated interviewees were in qualitatively quite different states at the different time points. In some interviews there was evidence of why a transformation occurred, for example Anne retired from work. However, for most interviewees transformation was only apparent from the process of comparative data analysis.

Many interviewees were also classified as the same type at different time points (see table 1). However, they were still adjusting their lives including their response to their chronic back pain. For example, at base line and six months Beatrice was classified as Past Reminders saying: “You’re not in control (despite) taking precautions. I went swimming (but then) I could hardly move ... that is frustrating”. However, during this time she became more confident in managing her pain “playing around” with medication. Leonard was classified as Becalmed at baseline and six months, resigned to his back pain continuing without improvement. However, between baseline and six months he had learnt how to recognize and manage his cyclical flare-ups.

Discussion

By listening to people with back pain or type 2 diabetes describe how they live with their condition it is possible to identify a dominant current dynamic, that is, the on-going process of adjustment when living with a chronic illness. We identified the following types of current dynamic: Stuck and Struggling, Past Reminders, Becalmed, and Submerged. Through comparison of individuals with back pain at different time-points we were able to discern transformation from one type of dynamic to another. By drawing on accounts of living with two quite different chronic illnesses, we have developed a typology that is not tied to a particular disease or health care pathway.

The typology was developed from interview data with people living with back pain or type 2 diabetes, so interviewees had more opportunity to talk about their life context than they might when seeing their clinician. In contrast to a clinician, the researcher was not offering health care so the interview data may have been less shaped by the desire for a particular intervention than an account offered in a consultation. We would argue that our typology more closely reflects the dynamics of life with chronic illness than idiosyncratic typologies developed by individual clinicians from their encounters with patients in the clinic.

Although the research team included clinicians and researchers with various backgrounds, a majority were family physicians/general practitioners. This may have resulted in analysis that

captured aspects of the interviews that family physicians/general practitioners considered important and the exclusion of other aspects. However, the analysis process was managed by a social scientist (AL), JS and SL provided alternative professional perspectives and the research user group members provided lay perspectives. Through the focus groups we validated and refined the typology with relevant patients and professionals but we did not return to the interviewees to review the typology.

Among those living with back pain, Stuck and Struggling was the most common type, but few of those living with diabetes were thus classified. This may be because the interviewees with back pain had recently attended their general practitioner to seek help with their back pain whereas those with type 2 diabetes were identified through the general practice disease register. During the final classification of interviews we found some interviews were similar to more than one type. Past Reminders were often present along with each of the other types of dynamic. However, with discussion, we were able to agree on a dominant type of dynamic for all interviews. Our sample of interviewees is small so it is possible there are other current dynamics of living with back pain or diabetes that we have not identified. However, we consider this unlikely as we had a diverse sample of interviewees.

Themes within our typology have been reported previously. The experience of being in limbo (52) while waiting for tests or diagnosis has been described. For those with back pain, often no cause can be found for the pain (53) but expectation of a diagnosis can slow recovery (33). Use of flexible pain management has been described (54) as has the fear of recurrence that can limit recovery from back pain (32). Severe back pain has been described as taking over a person's life, with the individual looking back to how things used to be and forward to what will no longer be (33). Acceptance of back pain is one aspect of effective behavioral approaches to back pain (55). For people living with diabetes, studies have described a sense of being out of control (56, 57). This can be made more distressing by the implicit assumption that it is the responsibility of the individual with diabetes to be in control (58). The use of routines for managing diabetes day to day has also been described (59) as has resentment of people with diabetes towards their illness, particularly where food is linked to cherished memories (60).

In reporting our results we have noted that transformation was something that was not necessarily noted or explained by the interviewees. We use the word transformation to describe change from one type of dynamic to another. However, this has much in common with the notion of transition described in a number of studies. For example, Kralik and colleagues (61) described the transition of women living with arthritis to a sense of order. McCann and colleagues (62) described how women in the first year following diagnosis with breast cancer go through transitions between having an identity as ill or healthy, and a transition to living into the future. Transformation has been described for people with a variety of chronic conditions (63) but here the notion of transformation incorporated the willingness and ability of the person to be transformed. Our analysis suggests that transformation for some people is not necessarily actively sought nor recognized at the time it occurs. Our notion of transformation is similar to that described by Kralik (61) who, from a study of women who identified themselves as living with chronic illness, described a process of transition from extraordinariness to ordinariness and back again in a recurring pattern and that these transitions were almost always unpredictable for the women.

Since the typology developed in our study included people with either back pain or type 2 diabetes, it may also be applicable to other chronic illness. Before our typology is used in clinical practice we would need to test its reliability for classifying patients. In itself a typology does not indicate what intervention is appropriate and when, although it could be argued that when combined with other clinical data it might aid the clinician and patient in decision making. For example, if a clinician classified a patient with diabetes as Becalmed, and the patient had

relatively normal blood glucose levels, the clinician and patient might agree on no change to the current approach to management. However, if a clinician classified a patient with diabetes as Becalmed, and the patient had recurring high blood glucose and so was at increased risk of the complications of diabetes, the clinician might challenge the patient to change their current self-management strategies. For people with back pain, Past Reminders that inhibit people taking appropriate exercise might respond to a cognitive behavioral approach (10) whereas for someone with diabetes, if Past Reminders prompt attention to diet and are not overwhelming, then no treatment is needed. Our typology has the potential to replace other less patient orientated typologies such as the acceptance – denial framework commonly used by clinicians and patients (64). To use our typology clinicians will need to actively listen for what their patient is saying about their current condition, which differs from diagnostic listening when the focus tends to be on the history of the condition.

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References

1. Ostbye T, Yarnall KSH, Krause KM, Pollak KI, Gradison M, Michener JL. Is There Time for Management of Patients With Chronic Diseases in Primary Care? *Ann Fam Med*. 2005;3(3):209-14.
2. Coleman K, Austin BT, Brach C, Wagner EH. Evidence On The Chronic Care Model In The New Millennium. *Health Affairs*. 2009;28(1):75-85.
3. Walker J, Holloway I, Sofaer B. In the system: the lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain*. 1999;80:621-8.
4. Massé R, Légaré F. The limitations of a negotiation model for perimenopausal women. *Sociology of Health and Illness*. 2001;23(1):44-64.
5. Greenhalgh T. Chronic illness: beyond the expert patient. *British Medical Journal*. 2009;338:629-31.
6. Parchman M, Romero R, Pugh J. Encounters by patients with Type 2 Diabetes - complex and demanding: an observational study. *Annals of Family Medicine*. 2006;4(1):40-5.
7. Upton J, Fletcher M, Madoc-Sutton H, Sheikh A, Caress A-L, Walker S. Shared decision making or paternalism in nursing consultations? A qualitative study of primary care asthma nurses' views on sharing decisions with patients regarding inhaler device selection. *Health Expectations*. 2011;14(4):374-82.
8. Stenner KL, Courtenay M, Carey N. Consultations between nurse prescribers and patients with diabetes in primary care: A qualitative study of patient views. *International Journal of Nursing Studies*. 2011;48(1):37-46.
9. Sturt J WS, Fox C, Hearnshaw H, Farmer AJ, Wakelin M, Eldridge S, Griffiths F, Dale J. . Effects of the Diabetes Manual 1:1 structured education in primary care. *Diabetic Medicine*. 2008;25:722-31.
10. Lamb S, Lall R, Hansen Z, Castelnovo E, Withers E, Nichols V, et al. A multi-centred randomised controlled trial of a primary-care based cognitive behavioural program for low back pain. The Back Skills Training Trial - "BeST". HTA, 2010.
11. Scott J, Cohen D, Diccico-Bloom B, Miller W, Stange K, Crabtree B. Understanding healing relationships in primary care. *Ann Fam Med*. 2008;6(4):315-22.
12. Lubkin I, Larsen P. *Chronic Illness: Impact and Interventions*. 5th ed. Boston: Jones and Bartlett; 2009.
13. Paterson B, Thorne S, Crawford J, et al. Adults living with Type 1 diabetes experienced transformation as an evolving process of responding to illness related challenges and as an outcome of a differentiation of self and body. *Qualitative Health Research*. 1999;9:786-802.
14. Hewson D. Coping with loss of ability: "good grief" or episodic stress responses? . *Social Science and Medicine*. 1997;44(8):1129-39.
15. Campbell R, Pound P, Pope C, Britten N, Pill R, Morgan M, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science & Medicine*. 2003;56:671-84.
16. MacFarlane A, O'Reilly-de Brun M. Using a Theory-Driven Conceptual Framework in Qualitative Health Research. *Qualitative Health Research*. 2012;22(5):607-18.
17. Adam B. Futurity from a Complexity Perspective. B Adam – web complexity futures - 2309052005.
18. Griffiths F, Borkan J, Byrne D, Crabtree B, Dowrick C, Gunn J, et al. Developing evidence for how to tailor medical interventions for the individual patient. *Qualitative Health Research*. 2010;20(12):1629-41.
19. Reeve J, Lloyd-Williams M, Payne S, Dowrick C. Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer. *Health*. 2010;14(2):178-95.
20. Mol A. *The logic of care: health and the problem of patient choice*. London: Routledge; 2008.

21. Griffiths F, Manazar U, Anton N, Chow E, Van Royen P, Bastiaens H. Understanding the diversity and dynamics of living with diabetes: a feasibility study focusing on the case. . *Chronic Illness*. 2007;3:29-45.
22. Scambler G, Scambler S. Introduction: The sociology of chronic and disabling conditions; assaults on the lifeworld. In: Scambler G, Scambler S, editors. *Assaults on the Lifeworld: New Directions in the Sociology of Chronic and Disabling Conditions*. London: Palgrave; 2010.
23. Corbin J, Strauss AL. Accompaniments of chronic illness: changes in body, self, biography, and biographical time. *Research in the Sociology of Health Care*. 1987;6:249-81.
24. Corbin J, Strauss A. A Nursing Model for Chronic Illness Management based upon the Trajectory Framework. In: Woog P, editor. *The Chronic Illness Trajectory Framework*. New York: Springer; 1992. p. 9-28.
25. Kubler-Ross E. *On death and dying*. London: Tavistock; 1969.
26. Bury M. Chronic illness as biographical disruption. *Sociology of Health and Illness*. 1982;4(2):169-82.
27. Bury M. Illness narratives: fact or fiction? *Sociology of Health and Illness*. 2001;23(3):263-85.
28. Charmaz K. *Good days, bad days: the self in chronic illness and time*. New Brunswick: Rutgers University Press; 1991.
29. Lawton J. Lay experiences of health and illness: past research and future agendas. *Sociology of Health and Illness*. 2003;25(3):23-40.
30. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ*. 2005;330(7498):1007-11.
31. Kelleher D. Coming to terms with diabetes: Coping strategies and non-compliance. In: Anderson, Bury, editors. *Living with chronic illness*. Boston: Unwin Hyman; 1988. p. 137-55.
32. Kendall N, Linton S, Main C. Guide to assessing psycho-social yellow flags in acute low back pain: Risk factors for long-term disability and work loss. Wellington, New Zealand: Accident Compensation Corporation; 1997.
33. Walker J, Holloway I, Sofaer B. In the system: the lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain*. 1999;80:621-8.
34. Schmidt H, Norman G, Boshuizen H. A Cognitive Perspective on Medical Expertise: Theory and Implications. . *Academic Medicine*. 1990;65:611-21.
35. Norman G. Research in clinical reasoning: past history and current trends. *Medical Education*. 2005;39(4):418-27.
36. Miller W. Routine, ceremony, or drama: an exploratory field study of the primary care clinical encounter. *Journal of Family Practice*. 1992;34:289-96.
37. Potter S, McKinlay J. From a relationship to encounter: an examination of longitudinal and lateral dimensions in the doctor-patient relationship. *Social Science & Medicine*. 2005;61:465-79.
38. Barry C, Stevenson F, Britten N, Barber N, Bradley C. Giving a voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor patient communication in general practice. *Social Science & Medicine*. 2001;53:487-505.
39. Dowrick C, Ring A, Humphris G, Salmon P. Normalisation of unexplained symptoms by general practitioners: a functional typology. *British Journal of General Practice*. 2004;54:165-70.
40. Smucker DR, Zink T, Susman JL. A Framework for Understanding Visits by Frequent Attenders in Family Practice. *Journal of Family Practice*. 2001;50(10):847-52.
41. May C, Allison G, Chapple A, Chew-Graham C, Dixon C, Gask L, et al. Framing the doctor-patient relationship in chronic illness: a comparative study of general practitioners' accounts. *Sociology of Health and Illness*. 2004;26(2):135-58.
42. Stange KC, Ferrer R. The Paradox of Primary Care. *Ann Fam Med*. 2009;7:293-9.
43. Stewart M. Towards a global definition of patient-centred care. *BMJ*. 2001;322:444-5.
44. Mead N, Bower P. Patient-centredness : a conceptual framework and review of the empirical literature. *Soc Sci Med*. 2000;51(7):1087-110.

45. Epstein RM, Street Jr RL. The Values and Value of Patient-Centered Care. *Annals of Family Medicine*. 2011;9(2):100-3.
46. Boreham N. Models of diagnosis and their implications for adult professional education. *Studies in the Education of Adults*. 1988;20:95-108.
47. Genero N, Cantor N. Exemplar prototypes and clinical diagnosis: toward a cognitive economy. *J Soc Clin Psychol*. 1987;5:59-78.
48. McGaghie W, Boerger R, McCrimmon D, Ravitch M. Agreement among medical experts about the structure of concepts in pulmonary physiology. *Acad Med*. 1994;69(10 Suppl):S78-80.
49. Sturt J, Hearnshaw H. Measuring Outcomes: self-management, empowerment and self-efficacy. *Diabetic Medicine*. 2003;20(suppl 2):78.
50. McConnell-Henry T, Chapman Y, Francis K. Husserl and Heidegger: Exploring the disparity. *International Journal of Nursing Practice*. 2009;15(1):7-15.
51. Adam B. *Time*. Cambridge: Poity Press; 2004.
52. Preston C, Cheater F, Baker R, Hearnshaw H. Left in limbo: patients' views on care across the primary/ secondary interface. In: Allen P, Black N, Clarke A, Fulop A, Anderson S, editors. *Studying the organisation and delivery of health services: research methods*. London/New York: Routledge; 2004. p. 62 - 71.
53. Lillrank A. back pain and the resolution of diagnostic uncertainty in illness narratives. *Social Science & Medicine*. 2003;57:1045-54.
54. Busch H. Appraisal and coping processes among chronic low back pain patients. *Scandinavian Journal of Caring Sciences*. 2005;19(4):396-402.
55. Vowles KE, McCracken LM, O'Brien JZ. Acceptance and values-based action in chronic pain: A three-year follow-up analysis of treatment effectiveness and process. *Behaviour research and Therapy*. 2011;49(11):748-55.
56. Campbell R, Pound P, Pope C, Britten N, Pill R, Morgan M, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science & Medicine*. 2003;56:671-84.
57. Savoca M, Miller C, Quandt S. Profiles of people with type 2 diabetes mellitus: the extremes of glycaemic control. *Social Science and Medicine*. 2004;58:2655-66.
58. Broom D, Whittaker A. Controlling diabetes, controlling diabetics: moral language in the management of diabetes type 2. *Social Science & Medicine*. 2004;58:2371-82.
59. Reach G. Role of habit in adherence to medical treatment. *Diabetic Medicine*. 2005;22(4):415-20.
60. Ferzacca S. Lived food and judgments of taste at a time of disease. *Medical Anthropology Quarterly*. 2004;32(1):41-67.
61. Kralik D. The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*. 2002;39(2):146-54.
62. McCann L, Illingworth N, Wengström Y, Hubbard G, Kearney N. Transitional experiences of women with breast cancer within the first year following diagnosis. *Journal of Clinical Nursing*. 2010;19(13-14):1969-76.
63. Dubouloz C, King J, Paterson B, Ashe B, Chevrier J, Moldoveanu M. A model of the process of transformation in primary care for people living with chronic illnesses. *Chronic Illness*. 2010;6(4):282-93.
64. Telford K, Kralik D, Koch T. Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing*. 2006;55(4):457-64.

| Table 1 Classification of interviewees with back pain at four time points over two years Pseudonym | Baseline | 3-6 months | 12 months | 24 months |
|---|----------------------|----------------------|---------------------------------------|----------------------|
| Ann | Stuck and Struggling | Becalmed | Past Reminders | Past Reminders |
| Beatrice | Stuck and Struggling | Stuck and Struggling | Becalmed | Becalmed |
| Charles | Past Reminders | Past Reminders | Becalmed | Moved out of area |
| Doris | Past Reminders | Lost to follow up | | |
| Edward | Past Reminders | Past Reminders | Self-reported as recovered | |
| Frank | Stuck and Struggling | Stuck and Struggling | Past Reminders | No invitation sent |
| Greta | Stuck and Struggling | Stuck and Struggling | Stuck and Struggling | Submerged |
| Heather | Stuck and Struggling | Stuck and Struggling | Becalmed | Lost to follow up |
| Ida | Stuck and Struggling | Past Reminders | No interview due to operation on back | |
| Julie | Stuck and Struggling | Lost to follow up | | |
| Kenneth | Stuck and Struggling | Submerged | Past Reminders | Becalmed |
| Leonard | Becalmed | Becalmed | Lost to follow up | |
| Monica | Stuck and Struggling | Past Reminders | No interview | Past Reminders |
| Nicholas | Submerged | Lost to follow up | | |
| Olive | Stuck and Struggling | Stuck and Struggling | No interview | Stuck and Struggling |