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Author(s): Frances Griffiths, Jeffrey Borkan , David Byrne, Benjamin F. Crabtree, Chris Dowrick, Jane Gunn, Renata Kokanovic, Sarah Lamb, Antje Lindenmeyer, Michael Parchman, Shmuel Reis and Jackie Sturt

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Tailoring Interventions

Developing Evidence for How to Tailor Medical Interventions for the Individual Patient

Frances Griffiths¹, Jeffrey Borkan², David Byrne³, Benjamin F. Crabtree⁴, Chris Dowrick⁵, Jane Gunn⁶, Renata Kokanovic⁶, Sarah Lamb¹, Antje Lindenmeyer¹, Michael Parchman⁷, Shmuel Reis⁸ and Jackie Sturt¹

¹Warwick Medical School, University of Warwick, Coventry, West Midlands, United Kingdom

²Warren Alpert Medical School, Brown University, Providence, Rhode Island, USA

³University of Durham, Durham, County Durham, United Kingdom

⁴University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School, New Brunswick, New Jersey, USA

⁵University of Liverpool, Liverpool, Merseyside, United Kingdom

⁶University of Melbourne, Melbourne, Victoria, Australia

⁷The University of Texas Health Science Center, San Antonio, Texas, USA

⁸Division of Family Medicine at the Bruce & Ruth Rappaport Medical School, Haifa, Israel.

Corresponding Author:

Frances Griffiths, Warwick Medical School, University of Warwick, Coventry, CV4 7AL, United Kingdom

Email: f.e.griffiths@warwick.ac.uk

Abstract

We aim to answer the question: How can we develop an evidence base that will assist tailoring health interventions to individual patients? Using social theory and interview data from people living with chronic illness we developed a new approach to analysis. Individuals were considered as emergent complex systems, adjusting and adapting within their environment and sometimes transforming. The notion of illness trajectory brought our attention to data in the interviews about the “emergent present”, the current period of time where all domains of life, from across time, have expression. We summarized patterns of adjustment and adaptation within the emergent present for people living with chronic back pain, depression and diabetes. We considered the potential of this analysis approach to inform medical decision-making. Our analysis approach is the first step in developing a categorization of individuals that might be useful in tailoring health care interventions to the individual.

Key words: illness and disease, experiences; qualitative analysis; complexity

Qualitative research has been used in many different ways for understanding health and illness and the impact of health care. The use of qualitative data collection and analysis can have a variety of goals (Starks & Trinidad, 2007). In this article our goal is to contribute to answering the methodological question: How can we develop an evidence base to improve the tailoring of health interventions to individual patients?

We developed this question from our clinical research on common chronic health problems that are often treated in primary health care: depression, diabetes and musculoskeletal disorders. When evaluated in clinical trials, interventions for these health problems show only modest benefit, even when the intervention has been developed from a strong research base. Examples include: Sturt et al. (2008) and the UK BEAM Trial Team (2004). Within this overall modest benefit, some individuals might benefit a lot and others not at all. The results of such evaluations are used to develop clinical guidelines, for example, Cost B13 project members (2006), National Collaborating Centre for Mental Health (2004) and the National Institute of Clinical Excellence (2002). However, clinicians often find it difficult to apply these guidelines to individuals. For examples see: Barnett, Underwood and Vickers (1999), Gonzalez-Leneku, Palacio-Elma and Lopez-de-Munan (2003), Thompson et al. (2000), Rosenburg (1998), Willis, (1995) and Summerskill, William and Pope (2002). Assessing patients as individuals is part of the traditional art of doctoring (Cassell, 2004) and patients want advice that is individually tailored (Massé & Légaré, 2001). However, there is little evidence on how to decide whether a particular individual, at a particular time, would benefit from a particular intervention or not (Fox, 2002; Griffiths, Green, & Tsouroufli, 2005). Recent UK guidance on treatment for low back pain (Savigny et al. 2009) suggests that the patient and clinician should choose between effective treatments but does not suggest on what basis to make the choice.

One approach to the above methodological question is to look for subgroups or categories of patients within a population that are most likely to benefit from an intervention. This has been attempted through person-centered statistical analysis (National Research Council, 2001) such as cluster analysis, using variables commonly collected within survey or evaluation research. For example, there have been many attempts to develop categories of back pain patients (Dunn, Jordan, & Croft, 2006; McCarthy, Arnall, Strimpakos, Freemont, & Oldham, 2004). However, a problem for this approach is choosing which variables to use for categorization. We wondered whether looking for a combination of variables was itself problematic. In this article we consider how it is possible to categorize people based on their qualitative state, by which we mean how each person is overall in relation to their illness. When we started this study, we did not know how we

might do this, so we read and discussed existing research and theory to develop our methodology and tried it out with empirical data. We describe the resulting analysis process in this article.

We worked with the idea that the individual themselves might be the best person to describe how they are (their qualitative state). We also wanted our resulting analysis process to be relevant to and even useful in clinical practice. We therefore decided to use research interviews with people living with chronic health problems as our data for trying out our analysis process. From the methodological research question we developed the following, more specific, questions:

1. How can we analyze what people say about themselves in relation to their chronic illness to enable us to categorize them in a way that takes account of how they are overall?
2. What categories do we find when we apply this method of analysis?
3. Is the categorization useful in the clinical setting to inform decision-making about an individual's use of health care interventions to maximize health outcome?

In this article we tackle the first question, explaining why and how we developed a method of analysis that will allow us to categorize individuals. To answer the second question more research is needed to apply the analysis method to data from patients and to categorise them. If this is successful then the third question could be answered through evaluative research.

Given the current lack of progress on developing categories within particular disease domains such as back pain, we looked to social rather than medical theory to help us develop the categorization. Our team included sociologists and primary care clinicians from three continents. We worked over several years in small groups discussing theory, examining interview data from our concurrent research, refining our analysis, returning to the theory and so on, in an iterative manner. For clarity, we describe the theory we used separately from how we developed the analysis approach. The finding we present in the article is the analysis approach which results in a summary of each person's qualitative state – how they are overall.

Developing the Approach to Data Analysis – Theoretical Considerations

Here we describe the theory used to develop our approach to analysis. There are three sections. The first describes theory about the nature of “the case” and how an individual could be considered a complex system. The second section considers theory about illness trajectory and relates it the notion of an individual as a complex system. The third section discusses the sociology of time and the idea of the emergent present.

The Case in Medicine: The Individual as Emergent Complex System

When a clinician and a patient make decisions about the use of a health intervention, the focus of the decision is most commonly the individual patient – the medical case. This was the focus our interest although we acknowledge that there are clinical situations where the focus of an intervention can be an anatomical structure, a family or population. We considered the individual as a “case” in the sociological rather than medical sense, with health and illness as just one aspect of the individual. The definition of a case is not without difficulty (Ragin, 1992). To define a case we need to consider how it is cut out of space and time, where to place a boundary around it to delineate it from its relationships with its context (Wieviorka, 1992). The boundary of an individual person might seem obvious, but many of their characteristics relate to how they interact with other people and their environment (Griffiths, 2009a; Griffiths, 2009b). Through our reading and discussion we decided that, for our categorization, we should consider the individual as someone constantly in the process of becoming, interacting with their context, relating to others and developing over time (Battersby, 1998; Meyers, 2004). The individual emerges through a “dynamic play of relationships that occur over time” (Battersby, 1998, p. 200), including feedback within the body as well as interaction with the physical and social environment. This notion of the individual can include self-reflection and the individual making decisions and taking responsibility (Benhabib, Butler, Cornell, & Fraser, 1995). Over time, the individual persists, although s/he changes qualitatively (Olson, 2008).

This notion of the individual has much in common with that of the complex system - “open systems with emergent properties and transformational potential” (Byrne, 2005). The emergent property of a complex system is the quality that indicates its nature as a whole, and cannot necessarily be predicted or explained by detailed examination of the parts of the system. There is constant interaction within a complex system and between the system and its environment and so constant change. The nature of this change might be small adjustments or adaptations but the system remains qualitatively similar. However, change might be transformational and, if this occurs, the system becomes qualitatively different. The nature or quality of the system is the emergent property of the system at that time (Byrne, 1998; Cilliers, 1998). Complexity science is concerned with describing and explaining the patterns of change of a system (Byrne, 2005), both the transformations and the adjustment and adaptation between transformations.

This social theory on the nature of the individual and complex systems, suggested that we could consider individuals as complex systems with emergent properties (what we have referred to above as how a person is overall, their qualitative state) that are constantly changing, and that the pattern of change might be important.

An individual's pattern of adjustment and adaptation, and any transformations, could result from all they do and all that happens to them over time. As this is similar to the idea of a trajectory (Byrne, 2005) we next consider existing research on illness trajectory.

The Illness Trajectory

The notion of trajectory has been used in life course studies with the aim of understanding social pathways within their historical contexts, and in particular how this impacts on human development and aging (Giele, Glen, & Elder, 1998), or families (Bengtson & Allen, 1993). Trajectories can be considered elements of the life course, with a life course composed of many interlocking trajectories (Elder, 1985). The notion of an illness trajectory has received considerable attention, particularly for its use in health care, for example: Burton (2000), Corbin (2001), Corbin and Strauss (1992), Corbin and Strauss (1987), Hyman and Corbin (2001), Robinson et al. (1993), and Walker (1991). This body of research recognizes an illness trajectory as one trajectory within a life course, interacting with all other aspects of a person's biography, and suggests that this interaction prompts individuals to continually develop new projections of their future that correspond to the projected illness trajectory. Chronic illness is described as something that changes over time, with the person moving from one phase of illness to the next when there is a transition in the disease state (Corbin, 2001).

The notion of illness trajectory is arguably limited by its focus on disease and the assumption that clinicians should aim to maintain the stability of illness (in the context of chronic disease), biography and everyday life activities. During our study we avoided focusing only on illness and considered that stability might not be an appropriate goal as a qualitative change in an individual's state, that is a transformation, might be needed to improve their health. With these reservations, we initially used the notion of illness as one trajectory within an individual's life course, and that a life course is punctuated by transitions (Elder, 1985). However, as we proceeded we were not convinced that examining the whole trajectory was relevant or possible in a clinical setting. Clinicians and patients make assessments and come to decisions about health care interventions at a particular time, based on what they know at that time. We therefore wanted to develop a method of categorizing individuals in present-time. We also wanted to avoid focusing on transitions, as clinicians often see patients with chronic illness when they are in between major changes. This led us to explore the sociology of time, particularly the work of Barbara Adam who considers the nature of time and complexity (Adam, 2005b).

The Individual and the Emergent Present

The present, it can be argued, is where a person lives their life, where the past has affected them and the future lies open (Wollheim, 1984). The present is something constantly changing as the present moves to the past and a new present is experienced. This concept of the emergent present is found in the work of George Mead (as quoted in Flaherty & Fine, 2001). For Mead, The present is what emerges from all that has gone before, and has a unique experiential quality that cannot be fully explained by the processes that have led up to it.

The emergent present is the product of the actions of individuals and the influences on them. Both actions and influences might have their impact over a wide range of time-scales, for example social upheaval occurring before birth, genetics, childhood, relationships and diet. The nature of these influences changes over time, for example, medical diagnostics and treatments, access to food or dietary fashion. In the emergent present the actions of an individual, and all that influences them from across time, find expression. We considered that if we were to capture this emergent present in our analysis, then all that acts to bring it about would, in a sense, also be captured even though they would not all be identified.

The emergent present could be thought of as an instant, something with no, or almost no, duration. However, within any point in time there is always duration (Abbott, 2001). We considered that the emergent present has duration and is a period of time where there is some sense of continuity (Adam, 2005a). This sense of continuity in relation to illness could stretch across time (Adam, 2005a), in the sense of calendar or clock time, but in terms of illness time, might be considered one point in time. Our reading of the sociology of time suggested that the emergent present could be defined as the duration of a persistent pattern of adjustment and adaptation, and could be characterized by this pattern. The pattern emerges from interaction, picking up traces of the pattern of change within the individual's environment including people, and the biological, physical, technical and cultural world (Lee, 1998). The pattern of adjustment and adaptation might be qualitatively different from the pattern for the same individual at other times or for other individuals, even those with a similar illness. We explored our interview data to see whether we could describe these patterns of adjustment and adaptation in the emergent present without needing to include the detail of who did what, when and why. We considered the boundary of the emergent present to be where a transformation had occurred from an earlier, different pattern of adjustment and adaptation. However, to describe the emergent present we found it was not necessary to describe the boundary.

We have introduced above, the theory we used to decide how to approach the analysis of interviews with people living with chronic illness. We also considered the social science literature on illness narrative to inform our analysis, particularly to avoid pitfalls for analysis that have been well described.

Developing the Approach to Data Analysis – Learning from Research on Illness Narratives

An influential account of chronic illness narrative is that by Gareth Williams (1984) who developed the notion of genesis of the illness narrative as in the following quotation (brackets are author's own):

In Aristotelian philosophy different levels of causality are conceived within an overall process of becoming which includes an account of the ends as well as beginnings and purposes alongside "causes". (Williams 1984)

Here, Williams refers to "cause" in "the modern sense . . . as it has generally been understood since Hume" (Williams, 1984). The genesis or becoming of illness narratives which Williams described has much in common with the notion of the emergent present, with the coming together of multiple influences across time. However, many studies of illness narrative analyse accounts from people where "the unfolding of illness comes to dominate people's experience of everyday life" and where there has been biographical disruption, "relationships between body, mind and everyday life are threatened" (Bury, 2001). Our interest was in chronic illness which, although constantly present for people in their daily lives, might not necessarily dominate it (Griffiths et al. 2007) and, relative to other experiences, might not be considered disruptive (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004).

Sociological research has identified many aspects of life that influence the illness narrative. These have been summarised by Julia Lawton and categorised into three groups: age and stage in the lifecourse; the macro-context including social norms and stereotypes (e.g., gender), history, sociopolitical context, socioeconomic context and culture; micro-influences such as marital relations and work relationships (Lawton, Ahmad, Peel & Hallowell, 2007). These are considered important within the lifecourse more generally (Giele & Elder, 1998). We argued that by focusing on the emergent present, it might be possible to capture in some sense all these aspects of life. What we hoped to capture was, at least in part, what Bourdieu meant by habitus (Jenkins, 2002), that is, acquired and durable patterns of perception, thought and action. Our analysis relied on the accounts of the individuals themselves and Bourdieu cautions us that habitus might not be accessible to the individual. However, this is not absolute, so the action of taking part in an interview, whether in a research or clinical setting, might have the potential to prompt reflection and perception about everyday life that is beyond what we would normally undertake during everyday life.

In his review, Michael Bury (2001), considered another issue when using illness narratives to understand the experience of chronic illness - the use of narrative to convey a message to the audience. He suggested that

illness narratives can have a number of functions. They can normalise either by describing life as similar to before the illness or by making illness a normal part of life, they can give the person a sense of worth, and they can be used strategically for mobilising resources from the wider social environment, including health care. Bury also identified narratives as moral: they are not necessarily consistent but are developed by people in relation to what is happening in their lives, and become a means to manage their fears of being considered “flawed”. Finally he suggested that all illness narratives, however complex and ambiguous, are so influenced by their cultural setting that they take on one of a number of genres that underpin all forms of narrative. He suggests three types: “stable,” almost mundane; “progressive” where the person is presented in a positive light; and “regressive” where there is increasing discrepancy between what is desired and what is possible in life. The implication of Bury’s analysis seemed to be that we might discover the purpose and nature of the narrative but not categories useful in health care decision making. However, how an individual currently talks about their illness, including the purpose and nature of their narrative, is all part of their emergent present. Our approach to analysis aimed to include this aspect of living with chronic illness, rather than seeing it as something outside of it.

Lawton (2003) gave advice on interpreting complex illness narratives, highlighting the importance of paying attention to the nature of the research encounter generating the accounts of illness, to “who is looking at whom and in what circumstances”. Using interview data was a limitation of our study as our analysis approach was ultimately intended for use in clinical settings. However, all our interviews were undertaken within the context of clinical research and so the data might be similar to, although more extensive than, the data from a health care consultation where there is shared exploration of the illness experience (Reeve, 2009). However, more research is needed to test the use of our analysis approach within a consultation.

In the remainder of the article we describe how we developed our analysis method including examples of how we used it with different sets of data during the process of development.

Developing the Approach to Analysis – using interview data

Our aim was to develop a method of analysing what people said about their health so in future research it would be possible to categorize them based on their emergent present. Here we describe how we used interview data to develop our approach to analysis. We first describe the data, then describe two stages of exploratory analysis. The first involved analysis of interviews for the illness trajectory. This led us to identify the emergent present. Within the emergent present we looked for the pattern of adjustment and adaptation. The second stage involved

looking at more interview data, of different types, to see if we could identify the pattern of adjustment and adaptation of the emergent present without the need to look at the whole illness trajectory.

The Interview Data

The team of authors had interview data sets gathered as part of stand alone interview studies, semi-structured interviews nested within clinical trials and structured interviews within a cohort study. Aspects of these studies have been published: Dowrick (1996), Dowrick, Kokanovic, Hegarty, Griffiths and Gunn (2008), Griffiths et al. (2007), Gunn (2006), Lamb et al. (2007), Sturt et al. (2008). All the studies had received ethical review within the system of the country where the study took place (United States, United Kingdom, Australia) and been approved. The interviews all explored the experience of living with chronic illness including the meaning it had for the individual. Interviewees had been recruited who had experience of at least one of the following: type 2 diabetes, low back pain lasting at least six weeks or depression. We randomly picked interviews from our data sets to use in developing our analysis approach, either using paper lots or asking an independent researcher to pick interviews using random numbers. This article reports how we developed the analysis approach rather than reporting the analysis of these data sets. We were using the interview data as a test bed for developing ideas and methods.

The Illness Trajectory and the Emergent Present

When first reading the interviews, it was not apparent to us how to identify what might be considered the emergent present. We therefore started by identifying the trajectory of the person and their illness. FG, SR and JB examined five interviews with people living with back pain and CD examined two interviews of people living with depression. The examples were discussed within the analysis groups (CD discussed analysis with FG), resulting in agreement about how to identify the trajectory. We did not undertake this analysis with all available interviews as our aim was to develop the analysis method. Here we provide two examples of what we did, drawing first on an interview with a woman about her experience of back pain and, then, on an interview with a woman living with depression. This is an extract from an interview with a retired woman living with her sister:

I cleaned those patio doors and the conservatory windows and it started the next day. I went to the doctor the day after, my general practitioner (GP) that is, and he gave me some muscle relaxants. Then I went back

again and he told me to stop taking those and to get pain killers. They did not work, they did not stop it, so I took myself down to the hospital and they x-rayed it and they said there was nothing there, it was probably torn ligaments and muscles. I put up with it for about another four days, I could not, I could not straighten up so all I did was go to the loo and back again to bed. Then I sent for the doctor and, well, I could not, I could not get to the surgery so they came out eventually after some arguing and he gave me a different type of pain killer and a friend then rang up about we were going to the theatre and my sister answered the phone. She said that I could not walk because of this. She (the friend) had something similar and she came round and she gave me the card of a chiro practitioner.

Having read the whole interview carefully, FG, SR and JB focused on this extract and summarised it (Table 1 first and second columns) referring to other parts of the interview if necessary for clarification. The first column of the table indicates calendar time as mentioned in the interview. We identified major changes in how the woman talked about her back pain and function by comparing descriptions of pain and function at different points in the extract, and marked these transitions (Table 1 horizontal lines column 2). Although it was straightforward to identify that a transition had occurred, for example the transition from being able to move around to being limited to bed, it was not always clear when the transition occurred or how long it took. We summarised the interviewee's description of back pain and function between each transition (Table 1 second column) and any interaction with their context related to back pain, for example health care, social relations and information exchange (Table 1 third column). We then summarised what was emerging from the interaction of the individual's back pain and loss of function with their context, in between each transition (Table 1 fourth column) in terms of the pattern of adjustment and adaptation.

The whole of Table 1 can be thought of as the illness trajectory for this woman. It is, of course, the trajectory as viewed by the woman from the time of the interview and interpreted by us. The final row in the table is the emergent present. Within this emergent present there is change for the individual but the pattern of change, how the woman is adjusting and adapting, is similar throughout the emergent present. The woman might have increased her activities during the emergent present, but the pattern of being careful and trying out normal activities was similar throughout.

INSERT TABLE 1 ABOUT HERE

For our second example we provide an extract from an interview with a person suffering from chronic depression and arthritis.

I feel dreadful. Arthritis spine and knees, and the weight does not help the doctors always tell me. I have tried every known diet, nothing works. (My GP) is thin as a pencil, she sits there telling me I need to lose weight. The pain in the back means I can not take exercise, even though I know I need it. I have no family here. Sister in (town), son in (city). Nobody to confide in or talk to at home. Get on well with the girls at work, but not to the stage where you can confide. So I mostly keep my worries bottled up. I have money worries, same as everybody else. Feel miserable. I do not go out much, cannot when I look like this. Often stay in my dressing gown all day. Most of this has come on since my divorce – over ten years . . . From then everything seemed to go downhill. Mainly being short of money. Married 17 years. My husband into his 40s, I do not know, the male menopause . . . went off with a girl of 18. Serves him right . . . she left him two years later. Worse the last 18 months, that is when I have felt really bad, since I started putting on all this weight. Feel I look so awful, do not go out at all. I retire in 18 months, all I can see is being at home, never going out. Do not see it is going to be much different. The only thing I enjoy is a weekend in London. I will go out there, to the theatre, eat out. Nobody knows me. Would not dream of doing that here. But there is not enough money to do it much.

This illness trajectory is presented in Table 2. It spans more calendar time than the back pain example, and includes the future. As with the back pain example, we were able to mark transitions in the illness experience and, between these transitions, we were able to summarise the pattern of adjustment and adaptation. Marking and then ignoring the transitions by focusing on the time between them, had the effect of drawing our attention away from aspects of the interview that were often the most dramatic – the transition points.

INSERT TABLE 2 ABOUT HERE

In Table 2 the emergent present is the penultimate row, the phase between a transition that occurred sometime since “18 months ago” and a transition in the future - on retirement. Although it is unclear exactly when the transitions occurred, by comparing data referring to different points in the trajectory, we found that the emergent present in Table 2, had a different quality to that of the past and future. In the next section we describe how we summarised the pattern of adjustment and adaptation in the emergent present without first accessing the illness trajectory.

The Pattern of Adjustment and Adaptation in the Emergent Present

From the analysis described above, we were sensitised as to how to look for data that told us about the emergent present. For this stage, we read different interview data and summarised the pattern of adjustment and

adaptation in the emergent present without first writing out a trajectory. FG, AL, MP and JS read and compared two semi-structured interviews undertaken with people living with diabetes. FG, JG and RK considered the data from four structured interviews with people who had identified themselves as living with depression. This data included responses to both open and closed questions. Each member of the analysis teams independently wrote a summary of the pattern of adjustment and adaptation in the emergent present. The teams then compared summaries, discussed how they had developed the summary from the interview, compared and refined the summaries.

The interviews with people living with diabetes started with the story of how they came to realise they had diabetes. We ignored this aspect of the interview, focusing on the years since that time. We found that after the upheaval of diagnosis and changes to their life following diagnosis, the remainder of the time described in the interviews had a similar pattern of adjustment and adaptation throughout. We summarised this pattern for one man as “erratic.” The following is an extract from his interview, illustrating this “erratic” pattern stretching into the past and future:

I can take it (blood glucose) in the morning and it is like 10.7 and the next morning I can get up and I have done nothing different and it is 14 (very high). And that happens all the time . . . me and the wife used to whip around the supermarket but not now. We look . . . first of all we look for no fat because of my blood pressure, no salt and particularly low sugar . . . It is very strange – very strange. How can I explain it? If you have got a broken leg you can feel it, you have got plaster on it, if you have got diabetes and nothing is happening. You can not really get to grips with - that you have got it, because I am feeling fine . . . (I have) a very stressful job . . . stress can have an affect on your sugar levels . . . if it does, I just have to put up with that. I mean I can not change the stress.

In contrast, we summarised a woman as “stable with occasional explainable high blood glucose.” She talked about her diabetes as follows:

Even when we go out . . . I mean, if we go on holiday or anything . . . well, all right I watch what I eat and I take a (blood glucose) test and that is it and it keeps it under control. Because I have got to take my tablets night and morning, so it is just if it goes up a little bit you just think back to the day before what you ate and then you think “Well I should not have had that” you know.

In these examples, we observed the interaction of various aspects of life. In these different aspects of life, change happened (or not) in very different clock/calender time-frames. For example, blood glucose changed from minute to minute but also had a pattern of change in response to meals which occurred 3-4 times a day. For the man, a “stressful” job which he had been in for years affected his diabetes, his family was a source of support day to day and week to week and over years or decades the availability of food, food processing and labelling of food changed. The woman talked about change in “going out” – a day to day, week to week activity, and taking holidays which occurred a few times a year. All these different aspects of life interacted and influenced the emergent present. The pattern of adjustment and adaptation emerged from the interaction of these different aspects of life, and perhaps other aspects not mentioned in the interview.

For the four people with depression we summarised the patterns of adjustment and adaptation in the emergent present as follows:

Held in a state of relative stability by high doses of antidepressants, contact with her GP, and her ability to seek help when she recognises signs in herself that she is becoming unstable. Stability is tenuous within her chaotic world.

In a different “place” from where he was prior to depression. Not able to do as much. Paces himself. Got here via physical illness then medication that precipitated him going into “overdrive” – too much happening, running around trying to do too much, on verge of chaos. Stopped tablets and to some degree this resolved but now in different place and planning to stay here.

Recovered yet not recovered, trying lots of different interventions herself to try and move on from this phase. Social interaction helps a little, including interaction with GP.

Moving steadily from something that triggered the depression symptoms (not specified but apparently not a catastrophic disturbance of life) toward resolution with the help of medication and talking.

The first three summaries suggest very little change, yet very different patterns of adjustment and adaptation. The first was a person only just held in a state of stability by the medication, health care support and her self-

awareness, but in constant danger of losing this stability. The second summary is of a man who seemed to be stable in his new “place”. The third suggests the person was rather stuck although desperately trying to move on. The fourth summary is of someone who was changing over time rather than staying the same, but the change is occurring in a steady way and in one direction so that the pattern of adjustment and adaptation remains the same.

Members of the team who had not been part of the first stage of analysis development were able to recognise what we were looking for in both structured and unstructured interview data and, through close reading of the text, to develop a summary of the patterns of adjustment and adaptation in the emergent present for each individual. For the same analysis in future we would undertake an initial coding of interviews for all that relates to the present time to make it easier to perceive the pattern.

Discussion

Patterns of Adjustment and Adaptation in the Emergent Present

In this article, we argue that for people living with chronic illness there is an emergent present related to their condition that can be described in terms of the pattern of adjustment and adaptation. Expressed within the emergent present is the interaction of the many different actions and influences that impact on living with chronic illness, including those that we can potentially name, and those we cannot name because we are unaware of them. In terms of clock or calendar time, the emergent present might exist very briefly, or might last over a long period of time. Within the emergent present, the pattern of adjustment and adaptation remains similar. This pattern can be described from interview data for different chronic diseases and the description does not need to include disease specific assessment. More research is needed to use our analysis approach on more data to see if these summaries can be categorised into groups that might be helpful for tailoring health interventions for individual patients.

Potential of this Analysis Approach for Clinical Practice

As a team we reflected on the potential for using this approach to analysis in clinical practice – might these summaries be useful for decision making? If the summaries might be useful then categories developed through more research might be useful. We recognized that we would need to check this with other clinicians and patients, but at that stage we drew on the clinical experience of the research team. We asked ourselves how we as primary care clinicians would respond to the individuals described above if we saw them as patients.

If attending to the woman with back pain (Table 1 final row) we would want to encourage her trying out normal activities. However, we might find it difficult to hear about the woman's emergent present from among the distress, anger and frustration expressed in her account, if we were not listening for it. If the woman with depression and arthritis (Table 2 penultimate row) consulted us, by focusing on the emergent present, we would avoid being drawn into the story about the past, but hear about the current low mood, pain and fear and respond to this, and hear that she has some support and distractions and encourage such social interaction and enjoyment. If we discerned the "erratic" state of the man with diabetes, we might at least be able to help to reduce his anxiety about his state even if we were unable to help him change it at present: this might include an explanation that blood glucose can change in a very erratic way, quite unlike the traditional medical model of homeostasis where increased blood glucose is considered explainable by diet, exercise or medication (Holt, 2002). For the woman with diabetes we might have little to offer at this time beyond ongoing support. Our response to each of the four people with depression would include providing a sense of continuity of care by being a witness to their experience of illness (Heath, 1995). The woman with tenuous stability might need a rapid response to relapse when requested by the woman herself. The man in a different "place" might only need to feel accepted as the person he is now. We might not know what specific therapy would help the third person but be prepared to wait and watch for when something changes. The individual moving steadily toward resolution might need continuity of contact as long as needed, but only perhaps for reassurance that the depression is resolving.

There are many different models of clinical assessment that focus on the individual within their sociocultural and historical context. Examples include: Allen et al. (2002), Cassell (2004) and Royal College of General Practitioners (1996). Clinical assessment can seek to engage the patient in their care through a patient centered approach (Mead & Bower, 2000). Discernment of the individual's current pattern of adaptation and adjustment is not explicit within these models, although it could be considered implicit as it forms an intrinsic part of assessing all aspects of an individual. We suggest that making the assessment of this aspect of a patient explicit has potential to help clinicians decide how to tailor health interventions for the individual based on their current pattern rather than on past patterns of adaptation and adjustment. As this aspect of an individual is not disease specific, its assessment might be particularly suited to primary health care. We suggest that decisions about management require clinicians to hear through a patient's account of past experiences to discern how the patient is adapting and adjusting in current time.

Conclusion

Our intention was to develop an approach to analysis that has potential to help clinicians and patients tailor medical decisions to the individual. We argue that by attending to the emergent present and, in particular, the pattern of adjustment and adaptation, clinicians and patients might be better able to tailor health care interventions without needing to clarify all the factors contributing to the emergent present. This requires attention to the individual case as a whole, with illness as the aspect of particular interest, rather than an approach that separates different aspects of the person for attention. We do not intend to imply inattention to what is known to be important for health, such as blood glucose level for diabetes, but rather that this is seen as one aspect of the emergent present.

As it stands, our approach to analysis is just another way of attending to and interpreting what patients say about themselves. However, as the pattern of adjustment and adaptation in the emergent present can be identified and summarised for each individual, it might be possible to develop a categorization based on these summaries. The next step will be to analyse data from more people and, through comparison of individual summaries, to try and develop a categorization, then check whether the categorization is meaningful and potentially useful for patients and clinicians. If it is, then it would need to be evaluated for its impact on health outcome when used in clinical practice for tailoring interventions to individual patients.

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Bios

Frances Griffiths, PhD, FRCGP, MB BS, BA, is associate clinical professor (reader) at the Health Sciences Research Institute, Warwick Medical School, University of Warwick, Coventry, West Midlands, United Kingdom.

Jeff Borkan, PhD, MD, is professor and chair in the Department of Family Medicine at Warren Alpert Medical School, Brown University, Providence, Rhode Island, USA.

David Byrne, PhD, AcSS, is professor of Sociology and Social Policy at the University of Durham, Durham, County Durham, United Kingdom.

Benjamin F. Crabtree, PhD, is professor and research director in the Department of Family Medicine at the Robert Wood Johnson Medical School, New Brunswick, New Jersey, USA.

Christopher Dowrick, BA, MSc, MD, CQSW, FRCGP, FFPHM, is professor of Primary Medical Care in the Division of Primary Care, School of Population, Community and Behavioural Sciences, University of Liverpool, Liverpool, United Kingdom.

Jane Gunn, PhD, DRANZCOG, FRACGP, MBBS, is the head of department, inaugural chair of primary care research and director of the primary care research unit at the University of Melbourne, Carlton, Victoria, Australia.

Renata Kokanovic, PhD, BA, is senior research fellow at the Faculty of Medicine, Dentistry and Health Sciences, Department of General Practice, University of Melbourne, Carlton, Victoria, Australia.

Sarah Lamb, PhD, MSc, MCSP, SRP, is professor of Rehabilitation and director of Warwick Clinical Trials Unit at Warwick Medical School, the University of Warwick, Coventry, West Midlands, United Kingdom.

Antje Lindenmeyer, PhD, MA, is a senior research fellow at the Health Sciences Research Institute, Warwick Medical School, University of Warwick, Coventry, West Midlands, United Kingdom.

Michael Parchman, is the Mario E. Ramirez endowed distinguished professor of Family & Community Medicine at the University of Texas Health Science Center, San Antonio, Texas, United States, and is an investigator at the VERDICT Health Services Research Program in the South Texas Veterans Health Care System in San Antonio, Texas, United States.

Shmuel Reis, MD, MHPE, is professor and chair in the Division of Family Medicine at the Bruce & Ruth Rappaport Medical School, Haifa, Israel.

Jackie Sturt, PhD, BA, RGN, is associate professor at the Health Sciences Research Institute, Warwick Medical School, University of Warwick, Coventry, West Midlands, United Kingdom.

Table 1: An Illness Trajectory of Back Pain

Calendar time	Description of pain/function	Interaction with context	Pattern of adjustment and adaptation
Day before pain		Cleaned patio doors and conservatory windows	
Day pain started	In Pain but able to move around (went to	Pain started	Able to function: testing out possible ways forward
Day 1	GP/hosp)	went to GP – muscle relaxants	
?Days/weeks later		returned to GP – pain killers	
For 3-4 days	Severe pain and	X ray at out of hours centre	Abandoned, dismissed, isolated
The next day	became limited to bed, only able to go to toilet. Needed care from sister. Described dramatically, as very severe, as very distressing	Phoned for GP – argued about visiting - came – gave pain killers. Cancelled theatre trip but at the same time gained information from friend who had similar pain and recommended chiropractitioner	except for one contact
? when/how long	Implication in interview of taking time to consider friends suggestion and becoming frustrated “I was not prepared to sit and wait”	Arranged to see Chiro practitioner: belief that back needed “treatment” not pain killers that “mask symptoms”	Stuck and frustrated.
Five weeks from start of pain, for three weeks	Got rid of pain, still there but not as bad, unable to drive herself to appointment	Visited Chiro practitioner who “did it.” Indicates pain killers helped	Experimenting with therapy, cautious about which activities she undertakes
Current time – eight weeks from start of pain	Can “drive and everything,” “still twinges,” “a bit delicate,” hurts if sits or walks for too long	Starting to resume normal activity	Careful but trying out normal activities

Table 2: An Illness Trajectory of Depression and Arthritis

Calendar time	Description of pain/function	Interaction with context	Pattern of adjustment and adaptation
Before depression		Married 17 years	
10 years ago	Depression started	Most of this has come since my divorce – mainly being short of money	Starting to go downhill
Intermediate time	Plus arthritis spine and knees	Pain in back means I can not take exercise	Destructive combination of depression and arthritis
18 months ago	Plus weight gain	Feels doctor not supportive, no family or confidants nearby	That is when I have felt really bad
Current time	Problems persist	“Feel I look so awful” – but get on well with girls in work, and can escape to London	Feeling “awful,” “bad,” “in pain” but also has support and distractions. Fears the future will be worse.
Future	Problems will continue	Retire in 18 months – All I can see is being at home –	Problems severe, but then support and distractions will disappear