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Living with chronicity and complexity: Lessons for redesigning case management from patients' life stories – A qualitative study

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Abstract
Rationale, aims and objectives Case management is commonly used to provide health care for patients with multiple chronic conditions. However, the most effective form of team organization and the necessary support structures need to be identified. In this respect, patients' views could provide a valuable contribution to improving the design of these services. To analyse the experiences of patients with chronic diseases and of caregivers, in relation to health care services and mechanisms, and to identify means of modelling case management services.
Methods
The method used was a qualitative study based on life stories, and semistructured interviews with 18 patients with complex chronic diseases and with their family caregivers, selected by purposeful sampling in primary health care centres in Andalusia (southern Spain) from 2009 to 2011.
Results

Three transition points were clearly identified: the onset and initial adaptation, the beginning of quality-of-life changes, and the final stage, in which the patients' lives are governed by the complexity of their condition. Health care providers have a low level of proactivity with respect to undertaking early measures for health promotion and self-care education. Care is fragmented into a multitude of providers and services, with treatments aimed at specific problems.
Conclusions
Many potentially valuable interventions in case management, such as information provision, self-care education and coordination between services and providers, are still not provided.

Introduction

Chronic diseases present a major challenge to health services. The consequences of the evident failure of conventional care models are avoidable hospitalization, an absence of care continuity and suboptimum results for patients [1].
Many studies have described models for chronic patient care and experiences in this respect [2], presenting a wide range of structures, with diverse levels of effectiveness [3,4]. In many cases, the main agents of health care are nurses, and the case management model is frequently used. However, doubts remain as to the most effective form of team organization and support structures [5].
Case management has reduced mortality rates for patients with cardiovascular disease [6], improved quality of life [7], enhanced functionality, medication handling and the use of community services, decreased institutionalization [8] and service use [9], heightened psychological well-being and enabled the detection of unmet needs [10]. Its effect on the demand for emergency attention remains unclear [6,11].
However, significant uncertainties remain: much research is based on local designs, and the target populations differ among studies, which makes generalization difficult [12]. Interventions are of a multifaceted nature, and so it is difficult to establish comparative reproducibility and the effectiveness of case management in chronic patients if the dose, frequency and elements of the intervention are not clearly defined [13].
In order to develop new services for case management or to refine those already existing, further research is required, incorporating a well-designed methodological framework for complex interventions [14] and taking into account the views of patients and caregivers. Patients can make a valuable contribution by providing information as to which aspects of their care are most important, on possible means of reducing complexity and on how to reinforce their own involvement in the process [15,16]. Chronic patients' perceptions of unmet needs have been associated with hospital readmission rates [17], and a frequent shortcoming of many disease management programmes is the inadequate adaptation of interventions to chronic patients' specific needs [18].
In modelling case management services, we should consider how patients and their families experience chronic disease, their relation with health services and providers, how they cope with difficulties, and how information is obtained and processed. Analysis of these information can be crucial to case managers' design of new interventions, making them appropriate to patients' needs. Because living with chronic illness has many episodes and aspects, a longitudinal point of view taking into account the patient's own voice can contribute detailed, valuable

background information. Accordingly, the theoretical framework of this study is inspired by the chronic illness trajectory framework (CITF) [19], under which, a chronic illness is viewed as a serious disease affecting a person's mental, emotional and social well-being, and a trajectory is a course of illness over time, together with the actions taken by patients, families and health professionals to manage or shape the course of this illness. During this trajectory, patients accumulate the effects of a chronic disease, which impact on physical, psychological and social aspects of their lives. This trajectory can be recalled by patients and recorded, to identify common phases through changes in health status and health care needs. In previous research, the CITF has been applied to diabetics [20], stroke patients [21] and the elderly [22].

This study forms part of a research programme aimed at identifying potential areas for redesigning the case management service of the public health care system in Andalusia (southern Spain) [23], using the Medical Research Council approach for modelling complex interventions [14], in the theorization and modelling phases, which contemplates the use of qualitative methods.

Nursing case management in Andalusia is based on a community approach, with coordinated service provision in health centres and/or patients' own homes [24], similar to the case of community matrons in the UK [25] or Guided Care in the USA [26]. Although the service is not specifically oriented towards people with complex chronic diseases, but towards patients with mobility problems, those who have recently been discharged from hospitals or are in terminal care, as well as towards patients' family caregivers, many of these patients suffer multiple chronic conditions, and reorientation is needed to target this population more explicitly.

Aim

The aim of this study was to examine patients' life stories in order to gain a better understanding of chronic disease experiences, both of patients and of their family caregivers, in relation to health services and the mechanisms developed to cope with the disease, so that new keys to model case management for patients with complex chronic diseases can be identified.

Methods

Design Qualitative study based on patients' life stories, starting from the onset of the disease and continuing to the present moment. This methodological approach, which has been used previously in patients suffering rheumatoid arthritis [27], provides a longitudinal view of the disease experience in the patient's own words, corroborated by those of the family caregiver. Qualitative inductive content analysis was performed.

The study was carried out in the provinces of Málaga, Almería and Granada (Spain), from 2009 to 2012.

Participants

Purposive sampling was carried out using the health centres' patient records [28]. The criterion for inclusion was that patients could be experiencing situations with high probability of complexity, such as the coexistence of several chronic diseases impacting on quality of life, the frequent interaction with health services, or the existence of health/social determinants [29,30]. Gender was also included as a selection criterion because of the proven differences in significance granted by

men and women to their health care events and to their process experience [31,32]. Purposive selection continued until information saturation was reached. During the interviews and the continuous analysis, an additional sampling criterion was incorporated, consisting of the selection of some cases with a high cultural level in order to examine certain aspects related to the patients' cultural level.

The case management nurses were asked to assess the degree to which the patients met these inclusion criteria. In addition, the nurses acted as mediators, contacting the patients and introducing them to the interviewers at the first meeting, after which the nurses left the interview. The main family caregiver was also present in the interviews.

Data collection

The interviews took place at the patients' homes or at their health centres (depending on the patients' preferences and functional conditions), after informed consent was obtained from patients and caregivers. The interviews were semi-structured [28], using a guide setting out discussion topics based on testimonies presented on the Health Talk Online web site [33], about living with chronic conditions. The research team also included contributions from case managers and nurses with experience in caring for people with complex chronic conditions and in home care. These topics were the starting point, but the interviews were conducted flexibly, and additional issues of interest that arose were also addressed.

The interviews started by recalling the outset of the disease, the patients' experience, perceptions and actions taken to cope with the new situation and the impact made on their lives. The discussion then considered the development of the situation, the action taken by patients, families and health professionals, the knowledge available about the disease, the self-care undertaken, any unmet needs identified, the changes and adaptations required, the type of care providers with whom they related, the barriers and facilitators encountered and the context and continuity of care.

The interviews took approximately 1 hour, divided into several sessions to avoid overtiring the patients. The interviewers annotated any circumstances, facts or elements of interest during the interview that could help in the subsequent analysis. With respect to reflexivity, care was taken to ensure the interviewers had no clinical relation with the interviewees because of the mutual expectations that this might generate, both during the interviews and in the analysis of results.

All interviews were digitally recorded and a verbatim transcript for further analysis was prepared, using ATLAS Ti 6.0 software (Scientific Software Development GmbH, Berlin, Germany), by a person unrelated to the research team. Throughout this process, all data were anonymized to guarantee confidentiality.

Analyses were carried out in Spanish and were subsequently translated into English for publication, as follows: once the document was completely drafted and analysed, the full version of the text was translated into English by two Spanish-native profesional translators. Their version was then reviewed and revised by an English-native translator. The participants' statements and testimonies sometimes contained colloquial language, and in the English version this register was maintained.

Analysis

A content analysis approach was adopted, following the principles set out by Taylor and Bodgan [34], implemented by one member of the research team. An initial reading was conducted to identify the topics that were mentioned. A coding scheme was then created for these topics. The codes were triangulated among the research team to achieve a consensus on their validity for the analysis. When two reviewers disagreed on a given coding decision, a third member of the team joined the discussion, and thus the codes were subjected to continuous refinement. Then, they were grouped into categories and subcategories. Finally, the data were interpreted according to the context in which they were collected, seeking possible influences of the researchers on the patients' discourse. All analyses were conducted using ATLAS Ti 6.0 software.

Credibility

Factors such as patients' expectations, lack of confidence in researchers, fatigue or memory shortcomings could reduce the credibility of the results obtained. To minimize potential limitations, various steps were taken. It was understood that subjects might have particular expectations about the study and try to adapt their narrative accordingly. To prevent this, they were given written and verbal information about the study aims before the interviews. Although they were not present during the interviews, the patients' case managers highlighted the purpose and features of the interview, and introduced the researchers. Considerable emphasis was placed on the importance of an open discourse, and it was stressed that what was said in the interview would have absolutely no effect on the usual health care provided. Furthermore, the researchers watched out for signs of exhaustion among the patients, in which case the interviews would be temporarily suspended. Cross narrative controls were implemented; thus, each interview took place in the presence of the patient's main caregiver in order to overcome any recall shortcomings. If the caregiver could not be present, an additional interview was scheduled for another occasion.

Ethical considerations

The study was approved by the Research and Ethics Committees of the Malaga Primary Health Care District and of the Andalusian School of Public Health. Informed consent was obtained from all participants.

Results

Of the 33 patients who initially met the criteria for inclusion in the study, 11 were rejected because of the inability to recall life story; in addition, one patient refused to be audio-recorded, two interviews were impossible to transcribe because of technical and/or intelligibility problems, and it was impossible to arrange a suitable appointment with one patient because of multiple hospital readmissions. Thus, the final sample was composed of 18 subjects (Fig. 1), seven men and 11 women, with an average age of 73.6 years.

Most of the patients presented chronic respiratory and heart diseases, together with comorbidities such as diabetes, renal insufficiency or arthritis (n = 16). Two patients had diabetes and cardiovascular processes, and no respiratory disease. Functional status was poor in most of the patients with heart failure or chronic

obstructive pulmonary disease (COPD)/asthma: New York Heart Association class III or higher in all the cases with heart failure, and moderate-severe COPD/asthma with forced expiratory volumen in 1 between 30 and 49%. Most interviews were performed at the patients' homes, because of their limited functional capacity (only two were carried out at the health centre). Caregivers were mainly family members: spouse (n = 13, 72.2%), son/daughter (n = 3; 16.6%). Two patients had no family caregiver, and none of the 18 patients had any formal caregiver support. All the patients were included in the home care programme provided by their health care centres belonging to the public health care system. This programme includes home visits by their family nurse, as well as a case manager follow-up, besides the care provided by their family physician and a social worker if necessary.

Socio-economic characteristics

In general, the participants' social context was that of working class neighbourhoods, and in some cases, of significantly limited living conditions. These socio-economic determinants were viewed as an important barrier by the participants, who were well aware that they were in an unfavourable position to apply material, cognitive and support resources to cope with the disease.

What can you do when you can't read and write, and you don't know anything? You don't realise . . . they can do whatever they want with you. (Male, heart failure, diabetes, neoplasia)

Here I am, stuck at home . . . It's really hard to move, I haven't been out for five months, because I'm on the fourth floor and there's no lift. (Female, chronic obstructive pulmonary disease, diabetes, hypertension).

Phases of the disease experience

In their experience with chronic disease, the subjects identified three transition moments: the onset of and initial adaptation to the disease, the phase in which changes take place in the quality of life, and finally, a phase of complexity.

The first phase generates a diversity of responses and coping mechanisms, with a prevalence of adaptive, self-initiated responses by the patients themselves, seeking remedies or presenting denial-avoidance. Progression of the disease has an additional effect on quality of life, secondary to functional impairment, impacting on daily life and disrupting family activities. With further advance of the disease, hospital readmission and further complications are critical periods (Table 1).

Adaptation to long-term disease

Among the adaptive and coping mechanisms developed in relation to loss of quality of life are resignation, resistance because of the presence of undertaking responsibilities towards other family members, and in some cases, information seeking. The existence of a family setting in which support is offered from the very start contributes to the coping process and helps patients comply with the treatment regimen (Table 2).

Self-care information

In processing and making use of the information obtained from health providers, information asymmetries often appear. Health care personnel are among the main sources of information and education about coping with illness, but their degree of

proactivity can help or hinder this process. In general, health care providers are not very proactive as regards the early promotion of measures for self-care. Pharmacies present another source of information and they are often seen as an accessible and personalized resource. The Internet, too, is increasingly used, especially when patients consider they are not obtaining enough information elsewhere. Those who are unable to manage computers may resort to family members for assistance. The information found by this means is not usually shared with health care personnel. Implementation of the treatment regimen requires time and effort of patients and their family caregivers. Diverse mechanisms to manage polymedication and appointments are deployed, and some patients generate their own skills in this regard, while others find it very difficult. Lifestyles can be a significant burden for patients, and are frequently maintained despite the initial appearance of disease, although the relentless advance of the condition often provokes a gradual shift to healthier habits, although nearly always when it is too late. This is particularly true of giving up smoking (Table 3).

Relations with health service providers

There exists a diversity of health providers and services, and a frequent problem is the lack of coordination among them and the fragmentation of care. Health care circuits are not designed to deal with complex, chronic patients, but are usually aimed at a specific problem and any event beyond what is habitually encountered tends to generate an unstable situation. When severe complications arise, and patients and family are unsure what to do, the emergency services are usually resorted to, thus increasing hospital readmissions.

The network of health care providers is extensive. The hospital physician is usually the best-identified and most highly valued by patients, while primary health care personnel tend to remain in the background. Case manager nurses are valued for resolving processes and arrangements, and for facilitating access to technical help and equipment.

A notable finding is that, despite the little proactivity facilitated and the scant information received on disease management, most patients express a high degree of acceptance and satisfaction with care providers. This may reflect their low expectation threshold in this respect.

Accessibility is one of the most valued aspects of health care, and the provision of telephone advisory services and teleassistance, enabling responses to be obtained without delay in situations of uncertainty, is greatly appreciated. The most requested form of accessibility is that of consultation with hospital specialists (Table 4).

Living with chronic disease: a trajectory model

From the global analysis of patients' life stories, a representation was constructed to describe the trajectory of persons who develop chronic diseases, the progressive complexity of their care, the elements that need to be strengthened, and the problems that must be addressed (Fig. 2). Prior life conditions and social determinants have an important effect on a person's capacity to cope with the first appearance of the disease and on their subsequent adaptation to its development. The disease requires a process of adaptation to the initial, obligatory changes in life patterns, including self-care. At this moment, information and empowerment are crucial elements to guarantee optimum disease management and self-care.

Complexity emerges when multiple interactions with providers and contexts of care start to produce inputs that generate lack of control and consequences on quality of life. Health care providers can operate with proactive interventions, or conversely, with a reactive approach. Other key inputs that make the system unstable, are poor coordination and continuity of care, severity of symptoms, or the absence of effective family support. If these factors generate positive inputs, complexity slows down and patients remain with acceptable levels of quality of life and empowerment.

Discussion

The aim of this study was to explore, through life stories, the chronic disease experiences of patients and their family caregivers, in their relations with health services and in the coping mechanisms developed, in order to identify key factors in modelling case management for such persons.

The persons who were interviewed clearly identified the different transition points in their life story with disease, from the outset to the final stages. Our findings are compatible with the CITF, in which the identification of the stages of their disease by persons with chronic illness is a key concept. The first stage in such a trajectory is usually defined as the period before the onset of symptoms, and consequently before a formal diagnosis is made [21]. In the present study, however, the first stage was taken as the onset of disease, a period when patients and caregivers still pay little attention to prevention. Apart from this difference, our findings coincide in many aspects with the CITF, with periods of stability alternating with challenges to health status, and a critical point after which the quality of life progressively deteriorates, until the terminal point is reached. Such trajectories do not necessarily follow a rigid sequence, and the phases can have their own dynamics, depending on various elements, such as those identified in this study. Other authors have used longitudinal qualitative techniques, and have reported a more poorly structured narrative by patients of their life stories with chronic illness [35]. It has been suggested that transformational learning processes or response shifts can produce changes in internal standards and values over time, which account for the transitions experienced by these patients [36].

The analysis of trajectories can facilitate the management of chronic illness, by identifying relevant factors and setting goals for the provision of care [19]; moreover, it can help identify processes and events with a potentially beneficial effect on disease control, as well as those where there is evidently room for improvement. In this sense, approaches as the complex adaptive chronic care (CACC) framework aimed to describe the interaction between patients and health care providers, within the broader health system over time, as a complex adaptive system [37,38], have permitted to detect early adverse changes in patient biopsychosocial trajectories [39]. Our results have concurred with some of the complex interactions that the CACC framework identifies related with patients instability, as well as the different and dynamic phases that encompass longitudinal patient journeys.

In the present analysis, coping mechanisms, the proactivity of providers, family support, the adequate provision of information and the continuity of patient care are shown to be the main areas in which interventions should be targeted during the course of chronic diseases, seeking to delay the loss of quality of life and the beginning of complexity. Following the Medical Research Council model for

designing complex interventions [14], the factors identified in this paper facilitates the identification and matching of case management interventions to the needs and demands of patients in the situations described. This aspect of the question is currently being addressed by the research team, and will be presented at a subsequent phase of the study.

Among the elements that determine the trajectories of persons with chronic diseases, coping and adaptation play a key role. Among the subjects examined, acceptance and resignation were the most common coping responses, possibly because at the time of interview, these persons were already at an advanced stage of disease. In people with chronic disease, coping responses can generate positive impacts, such as affectivity, functionality and life satisfaction in various domains. Cognitive strategies used by chronic patients include the search for benefit or personal growth despite the disease, as part of the shift response [40]. Some authors have highlighted the importance of helping people with chronic disease to find a meaning within the process and to perform a positive re-assessment, as key elements in maintaining hopefulness [41] and case management should incorporate interventions to promote and reinforce this area. Most of the time, patients and their families are alone, with no support from the health care system. Therefore, knowledge of their mechanisms of adaptation to disease is essential, so that they may be strengthened or reoriented [42].

One of the major areas in need of improvement is the level of information and education for self-care that is received by patients and caregivers. This aspect has been perceived as a cornerstone of chronic disease care for many years, but the situation remains very unsatisfactory. Educational initiatives have achieved good results in the field of self-care, but there are still many uncertainties about which active components should be included and about the most effective forms of care provision [43]. Any initiative in this sense should be well grounded on theoretical models and focused on the patient, and at present these requirements are by no means assured [44].

The lack of information and of recommendations for patients and their family might be alleviated through structured care planning, but this issue is often ignored in studies in this field [45]. This aspect is directly related to how the treatment regimen is organized and implemented; whether this is done well or badly, it plays an important part in the daily life of chronic patients and their families [15]. Nurse-led interventions have achieved encouraging results in the improvement of adherence to medication by chronic patients [46], and this should be a systematic component of case management.

A noteworthy aspect of our findings is that of the barriers existing to changes in lifestyles, as a result of which many opportunities are lost in the initial phases of the disease. Group and individual interventions in primary health care and community settings are useful for empowering people to change their behaviour patterns with respect to health risk factors [47].

Our study shows that family support is an important resource for coping with chronic disease, especially when other health and social resources are lacking. However, the family response does not always produce positive results in patients. Therefore, care provision should stress the importance of family cohesion and of self-effectiveness to cope with the situation and to improve response capacity, as this will facilitate positive results for the patients [48].

Health care continues to be fragmented into diseases, specialities and bounded areas, and patients clearly perceive the impact of this on their lives. In consequence, they will often take personal initiatives to avoid additional problems, for example through the selective use of certain services. This problem has also been reported in previous studies [5].

Despite the efforts made to redirect nursing services towards a chronicity approach, and the existence of case management services, many patients continue to believe that the solution to their problems can be found in the context of acute care, in which the specialist physician is the main point of reference. This attitude has been observed even when the multiplicity of specialists and the resulting fragmentation of health care produce clearly adverse consequences. The same situation has been identified in international studies. Such a perception could be due to the bias generated by familiarity with what is most commonly encountered, that is acute care [49], and therefore patients and caregivers do not conceive of other forms of care provision.

Our study presents certain limitations, mainly arising from the characteristics of the patients in the study sample. Their expectations of obtaining some kind of help for their condition could have generated an excessive emphasis on the negative aspects of the situation, although the methodological precautions taken by the research team, together with the life story approach, focused on the entire experience with the disease, would have limited this problem. Furthermore, during the data sampling process, many patients had significant difficulty in recalling their experiences, and were excluded from the final analysis. Nevertheless, information saturation was not compromised by this issue. Finally, the health care context recounted by the study subjects is specific to Spain and could have particular distinguishing characteristics, although the problems identified by the patients mostly coincide with the findings of international research in this field.

Conclusions

The results obtained reveal a situation in which many interventions that could greatly help patients and their families, such as information provision, self-care education and actions to enhance coping and adaptation mechanisms, are not still assured. Moreover, it is apparent that much remains to be done to reorient health services towards chronicity, increasing the flexibility of health service organization in order to provide an integral response to complex, unforeseeable scenarios and to ensure a proactive attitude is taken by health care personnel.

The profile of end users of case management services in Spain corresponds to older people, with impaired functionality and an elevated frequency of episodes and interactions with the Health Care System. These features constitute a challenge for the inputs offered by the providers to the system, as the expected outcomes need to be coordinated and adapted to them. These results show that for the redesign of case management services, no reductionist approach should be used, and a complex system perspective is needed to tackle the diverse and unpredictable factors that determine the care of people with multiple chronic conditions.

Implications for practice

The results of the study highlight the need to provide support to people with complex chronic conditions and to the caregivers involved. Areas of necessary

improvement in clinical practice are clearly identified, many of them suitable to case management and which could be incorporated in case management standards for this population. Identification of factors that influence the trajectories of persons with chronic illness, as addressed in this study, could help case managers set targets to address important needs, which are currently unmet, that have been identified by patients and caregivers in the course of their relation with health services.

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Figures and tables

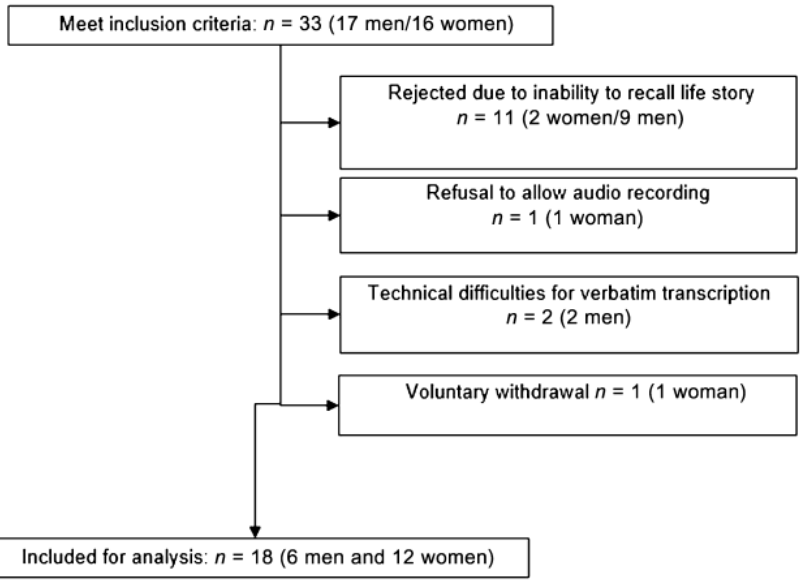

Figure 1 Sequencing for selection and recruitment of the sample.

Table 1 Transitions in living with chronic illness

Categories and subcategories	Life stories
Phases of the disease experience	
First period: different responses and coping mechanisms	'. . . it started in 1981. When I was walking, I felt terrible. My heart started to fail, and they said I had high blood pressure, but I didn't pay much attention. I went to a cardiologist and he said, "How can you stand up?" But I stopped going to the appointments . . . It was mostly my own fault.' (woman, heart failure)
	'My doctor told me, "I've examined you and there's something unusual when you breathe. You should see a cardiologist". Can you imagine, me, with six children? I wasn't going to bother with doctors, because there wasn't anything wrong with me. I didn't take any notice.' (woman, heart failure, asthma, diabetes)
Second phase: impact on quality of life	'Being here is like being in prison, I'm always shut in, for two or three months at a time . . . When I'm walking, I have to stop and rest every two minutes, because I can't breathe and my legs are wobbly.' (woman, heart failure, COPD)
	'And now I can't manage. I had to take it easy even when I was making love with my husband, I just couldn't do it.' (woman, heart failure)
Final phase: complexity	'The oxygen, the breathing machine at night, hooked up to a machine all my life. That's what I do; and being a bother to my children and not letting anyone get on with their lives'. (woman, heart failure, COPD)
	'Every month I have to be readmitted: for 8 days, 12 days, 18 days . . . I've only called an ambulance twice. We nearly always call a taxi and go to the hospital. In Accident & Emergency, they recognise me straight away.' (male, heart failure, diabetes)
	'It's true, I used to smoke with the oxygen attached. Then, once I it lit a cigarette and it flared up, and burnt my face, my ear and my hair. I couldn't breathe; they took me to hospital and I had to stay there for a month.' (female, COPD, rheumatoid arthritis)

COPD, chronic obstructive pulmonary disease.

Table 2 Ways of coping and adapting to chronic illness

Categories and subcategories	Life stories
Coping and adapting	
Coping mechanisms	'If you look at it positively, and think this is what's happened to me and I've got to get over it, then that's that. I won't change anything by getting angry or frustrated, this is what there is. I don't know, maybe it's that sort of thinking that helps me.' (woman, heart failure, renal insufficiency)
	'I had a bad time, but it wasn't the end of the world. I got depressed when my mother died, but until then, the things that had happened to me didn't get me down. I've had it bad, but because I had to look after my mother, that gave me strength, it was the reason for living.' (woman, COPD)
	'I didn't give in, because when you're ill, what you have to do is to find out about it; not fight it, but make friends with it, so that the disease doesn't hurt you, it helps you.' (woman, COPD)
Family support	'She's the one that helps me [referring to his wife]. [She adds] I have everything written down and I prepare it because sometimes he forgets.' (man, heart failure and his wife)
	'In the family, we've been doing everything for her for five years, because we can't . . . we have to move her, take care of her . . .' (family caregiver of woman with heart failure).

Table 3 Self-care and management of treatment regimen

Categories and subcategories	Life stories
Information for self-care	
Information asymmetry and low proactivity by providers	'The doctor said to me "Your heart is very large and you've got to lose weight". But how am I going to lose weight? They didn't explain what kind of life I should live.' (man, heart failure, diabetes)
	'I learnt to use the inhalers by reading the information leaflet. Nobody told me how to use them. The doctor never told me anything.' (woman, COPD, rheumatoid arthritis)
	'At that time I didn't know anything about my disease. I asked, but they always used so much jargon . . . I came out the same as I went in, in the dark.' (man, heart failure)
Pharmacies: a source of information	'My pharmacist has given me most explanations about the medicines I take. Not the doctor and not the nurse. He is a good friend. I can rely on him.' (man, heart failure)
	'The man in the chemist's is the only one I ask. He knows all about these things. And he reads me out the information leaflet, too.' (woman, asthma, diabetes)
Internet information	'We're going to do this test', they said, but they didn't tell me what it was and they didn't explain it to me. I've never had a computer, but my brother has one and he's told me all about my illnesses. But I haven't told my doctor or the nurse . . . I looked it up and if something wasn't the same, I didn't do anything, I'm fairly quiet, I don't want to make trouble. (woman, COPD, rheumatoid arthritis)
Treatment regimen	'I keep all the papers in a folder. Every morning, I put the pills I have to take in a little box and I take them during the day. And then the equipment and the injections.' (woman, asthma, diabetes)
	'In the evenings, I take the blood pressure pill, the one for cholesterol, the metformin. She [his wife] gives them to me, I don't have to worry. If she ever spends a night away from home, I don't take them because I don't even know where she keeps them. I even don't know the dose I have to take.' (man, diabetes, peripheral arterial disease, hypertension)
Lifestyles	'I was told I had COPD but I carried on the same, because the problem wasn't that serious. I kept on smoking, even though time and time again they said I should stop' (woman, COPD)
	'I have problems with the insulin. They haven't told me if I take too little or too much . . .. The aspirin is to make my blood more liquid, but I don't know if it causes problems or not . . .. The urine pill is to eliminate liquids but I don't know why I have to eliminate them.' (woman, COPD, diabetes)
	'To be honest I didn't want to stop smoking. I said, I don't drink, I don't go out, my only vice was my cigarettes, and only eight or ten a day.' (woman, COPD)
	'They told me to walk for half an hour every day, not too fast. . . . So, I did. The diet . . . that was really hard to get used to. The diet, yes, that was terrible.' (man, heart failure)
	'I was told to give up smoking, to go on a diet. . . . And to live a healthy life, to go for walks . . . But, I didn't pay attention. Sure, I had good intentions, I said, "I'm going to change"; the problem is, I do everything, except smoking, I can't quit.' (woman, heart failure, COPD)

COPD, chronic obstructive pulmonary disease.

Table 4 Navigation across health services

Categories and subcategories	Life stories
Relations with health services	
Fragmentation	'Sometimes, when you say, "But look, he's got kidney disease, too", they tell you, "Well, we're here to look at his heart, the kidneys are not our concern".' (caregiver of man with heart and kidney failure)
	'Every time I see a doctor, they give me drugs. I have the Pain Unit; if the rheumatologist has prescribed something, the Pain Unit takes it away and gives me something else. And each doctor I see gives me more . . .' (woman, COPD, chronic pain)
	'The information system doesn't work; I've been many times and I've told the doctor, "Look, give me this to give to my GP". And he says, "No, she's got it already in her computer". And when I go, I always take a photocopy of the report because it turns out it isn't in the computer. And I have to tell the story all over again.' (woman, COPD)
Health care circuits are not adapted to complex chronic patients	'The real problem is that when I was in hospital, I was treated for, maybe, suffocation, but they didn't take into account the osteoporosis. I've had to fight, saying, please, at least get me the patches, because they only treat me for one thing and not the other.' (woman, COPD, osteoporosis)
	'The only thing I see wrong is that he gets sick and we have to call the Emergency Service, and they don't know anything about him. Yes, they're doctors, but they don't know about his disease.' (caregiver of man with heart failure)
	'I don't like going to the Emergency Service because they leave me there, sitting on a chair, they give me a spray, and that's all. Ten hours sitting on that chair . . . and they don't know about you . . . I remember, once, a young girl examined me and said, "There's nothing wrong, but since it's late, you can stay here for the night", and I ended up in hospital for two months "because there was nothing wrong".' (woman, COPD)
The providers' network	'In the last six months he's had lots of ups and downs and we end up calling the Emergency Service . . .. They come and when they see it's something serious, then they take him.' (caregiver of man with heart failure)
	'I've been seeing a cardiologist for 18 years, and it's like when you give someone pills and they don't do any good, but you get well.' (man, heart failure, diabetes)
	'The best thing to do is to see a specialist. Not the GP, but a specialist.' (man, heart failure)
	'When I'm admitted to hospital, the nurses don't explain anything. One of them comes along, sticks a tube in your arm, gives you a jab and that's all.' (man, heart failure)
Accessibility	'She [the case management nurse] comes and visits us at home, that helps a lot. We're very satisfied. With the way she talks to us, "You've got to go to such and such, I'll give you a form, go to X and tell him I sent you". She organises everything. We've been with her for years, and she's always there to help.' (man, heart failure)
	'I think it's quite simple. Someone with a complication like this, you can't give them an appointment for 6 months later (. . .) What's most needed is for the specialists not to take so long.' (woman, heart failure)
	'What I believe is wrong is that he gets sick and I can't phone the doctor, not even so he can tell me what's the best thing to do at that moment.' (caregiver of man with heart failure)
	'I called tele-assistance and the Emergency doctors came straight away . . . We are very happy. I feel safer with this because you can tell them what's happening and if they have to send the ambulance, they do.' (man, heart failure)

COPD, chronic obstructive pulmonary disease.

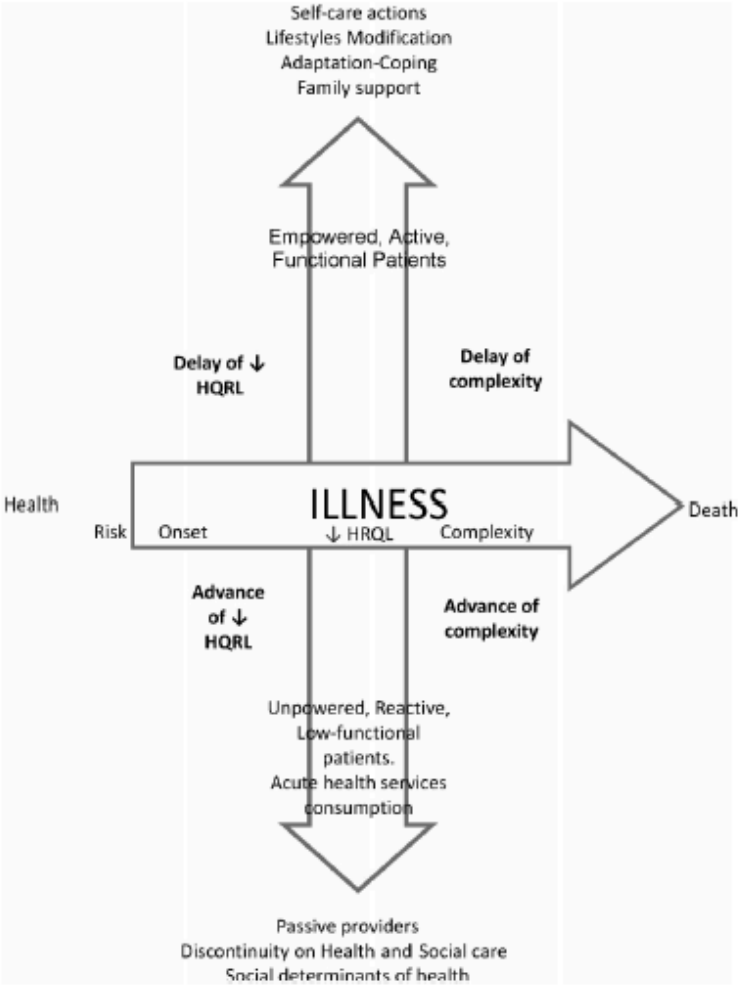

Figure 2 Factors that affect complexity across lifecourse with chronic illness. HRQL, health-related quality of life.