

RESEARCH PAPER

Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness

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Background: Patient education self-management programmes draw on sociological understanding of experiencing single chronic illnesses, but health practitioners do not always recognize the tensions and ambiguities permeating individuals' management experiences, particularly for those with multiple morbidity. The aim of this study was to illuminate how people negotiate multiple chronic illness, and everyday life.

Methods: A sample of 23 people in their early 50s was recruited from a community health survey in Scotland. The participants had four or more chronic illnesses and were interviewed twice. The qualitative data that were generated highlighted the impact of illness and associated management strategies, as people attempted to continue familiar lives. Analysis was based on constant comparison and informed by a narrative approach.

Results: People used multiple techniques to manage symptoms and conveyed a moral obligation to manage 'well'. However, maintaining valued social roles, coherent identities and a 'normal life' were prioritized, sometimes over symptom containment. This led to tensions, and participants faced moral dilemmas as they self-managed.

Discussion: Self-management policies, programmes and healthcare practitioners need to recognize the tensions that people experience as they negotiate symptoms, valued social roles, positive identities, and daily life. Addressing these issues may improve opportunities to support patients in particular contexts, and enhance self-management.

Keywords: Identity, Moral work, Multiple chronic illness, Self-management, Social roles

INTRODUCTION

The twenty-first century has seen policy responses to the rising prevalence of chronic illness emphasizing initiatives such as chronic illness self-management programmes, which increase the extent to which patients actively manage their own illnesses. Many, such as the UK Expert Patient Programme¹ and the Stanford Disease Self Management Programme² on which it is

based, draw on a sociological understanding of the work that people with chronic illness already do to manage their problems. As Lorig and colleagues write, 'One cannot not manage ... it is impossible not to manage one's health. The only question is how one manages'³ (p. 1).

Most research from patients' perspectives on the experience of chronic illness has focused on how people try to manage single conditions. For example, research shows how individuals experience: the strategic management associated with diabetes;⁴ the stigma of epilepsy;⁵ the loss of basic physical capacities with Parkinson's disease;⁶ the physically burdensome, unpredictable and

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often 'invisible' rheumatoid arthritis;⁷ and the emotional and debilitating effects of depression.⁸ However, the research also reveals how people with different chronic illnesses share fundamental concerns about their functional abilities, and maintaining 'normal' lives.⁹ Chronic illness can be disruptive, as individuals find that they are unable to perform previously taken-for-granted behaviours.¹⁰ When symptoms lead to a lack of bodily control, activities and routines are often limited, which can challenge one's sense of a 'normal' life.⁹ When individuals can no longer perform familiar tasks, fulfil roles, and live 'normal' lives, self-concept is challenged, and a coherent sense of self can be lost.^{10,11} Such experience has implications for how people respond to ongoing illness.^{9,10,11}

The literature also documents how people describe using both emotional and practical strategies to manage living with chronic illness. Individuals relate the importance of 'attitude' as they strive to maintain familiar lives. They speak of refusing to 'lie down' to illness,¹²⁻¹⁴ and convey how practical efforts to manage, mask and alleviate symptoms colour the chronic illness experience.^{4,7,9,13-15} This often means adopting techniques to conceal one's limitations or differences from people during interaction.^{7,16} West¹⁶ has shown how people who suffer with epilepsy attempt to pass as 'normal' as far as possible, and how techniques to deal with events in daily life mean avoiding particular situations and covering particular behaviours. Likewise, Wiener's study⁷ revealed that individuals who suffer from arthritis employ ways of playing down impairment and maintaining appearances; in attempting to function 'normally', people risk and endure discomfort. Research testifies that people attempt to 'keep up appearances', struggle with symptoms, and emphasize their healthy status through normal activities.¹⁷ Trying to 'keep busy' is a strategy used to resist illness.^{17,18} However, what 'keeping busy' entails may change. Pacing (regulating activities) is often

adopted by people in order to be able to function. Charmaz found that people described adjusting to a less active daily life, routinely adopting coping techniques and renegotiating what they perceived 'normal' to be.¹³

Based on their findings on the process of chronic illness management, Corbin and Strauss¹⁹ identified three lines of 'work' made up of interconnected and overlapping tasks: illness work; everyday life work; and biographical work. They suggest that these are 'inextricably linked and reciprocally interactive'¹⁹ (p. 90). As people undertake illness work and manage their symptoms and regimens, they also attempt to maintain their daily lives in terms of tasks and roles. Biographical work reaches beyond the medical trajectory of illness, relating the present to a remembered past, and an anticipated future, and encompasses the process of identity work as people come to terms with illness on an emotional and a practical level.

Others have considered a moral dimension to the chronic illness experience.¹¹⁻¹⁴ Symptoms are commonly voiced as something to be struggled against, and to be controlled;^{20,21} people express their desire to be perceived as credible patients in the medical encounter,^{22,23} and as medication users.²⁴ They also convey a need to demonstrate their moral worth as individuals. For instance, Robinson²⁵ reported how people with multiple sclerosis felt at risk of being labelled as mentally ill, malingerers or 'drunk'. Additionally, an inability to fulfil social roles and carry out tasks can have existential implications, posing a threat to one's favoured identity.²⁶⁻²⁸

This paper draws on the research reported above, and contends that *moral work* is integral to the illness, biographical and everyday 'work' detailed by Corbin and Strauss.¹⁹ We recognize that illness management takes place in daily life, and in social and cultural contexts structured by moral guidelines. The participants conveyed the importance of 'managing well'. They reflexively drew on emotional and practical

resources as they worked to negotiate illness, daily life and their moral integrity. This paper also considers the experience of living with multiple chronic illnesses relatively early in life (all participants were in their early fifties at the time of interview).

a measure of socio-economic status (the Table gives a brief summary of participant characteristics).

A three-stage process was used to collect the data. First, a semi-structured interview covered three overlapping topics: conditions and symptoms, the impact of conditions on daily life, and the use of formal services.

Second, participants were invited to complete a 2-week self-completion symptom/management diary. Finally, a second semi-structured interview conducted approximately 3 weeks after the first meeting allowed greater focus on management of symptoms. All interviews were conducted by AT. The diary comments were not analysed in detail, but were used as an *aide memoire* for the post-diary interview. The three-stage process ensured coverage of topics, and allowed individuals to talk about their experiences in detail. Two interviews investigated illness onset, development and help-seeking.

The second interview allowed participants to reflect on their initial accounts, and fostered opportunities for clarification. A 2-week diary was considered the optimum length of time to gain data, and to limit participant burden.³⁰ Of the total sample ($n=23$), 20 took part in two interviews, and 14 completed or partially completed the diaries.

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Ethical Issues CONVITATO ETICO

Ethical approval was gained from the University of Glasgow Ethics Committee. Information sheets were mailed to sampled participants, who were telephoned approximately 4 days later, to check their willingness to participate. For those who were, further details of what their involvement would include was explained orally, and an appointment was made for a time and place of their choosing (usually their home). Participants provided written consent prior to the interview and were given opportunities to withdraw at each stage of the research process. The interviews involved talk around more negative aspects of participants' lives. With this in mind, there were attempts to

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METHODS

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Sampling and Data Collection

The research reported here forms part of a study that investigated how people with multiple chronic illness, but contrasting rates of general practice consultations, manage illness and make use of the general practitioner consultation. Forty-one participants were purposively sampled from a longitudinal community health survey in the West of Scotland, the Twenty-07 study,²⁹ on the basis of responses given during data collection in 2000–2003. All had reported four or more chronic illnesses. Twenty-three people took part (13 women and ten men). Of the 18 non-participants, three could not be contacted, eight refused, mainly due to time considerations, and seven were unavailable at the allotted time, but were willing to take part if needed subsequently.

In order to examine the experiences of people who had different general practitioner consulting rates, half of the participants had frequent (defined as seven or more consultations) and half had less frequent (three or fewer consultations) consultation rates in the previous 12 months. As the participants were all in their early 50s, it was hoped that data would be generated that would aid our understanding of how chronic illness is experienced by a relatively young group with social responsibilities and obligations (12 were employed, and 22 were parents of school-age children or young adults). Because early interviews suggested that experiences also varied with gender and socio-economic circumstances, sampling also attempted to achieve equal numbers of men and women and of people living in rented and in owner-occupied housing as

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TABLE. *Characteristics of the participants*

Pseudonym	Housing tenure	Conditions reported at wave 4 of Twenty-07 study 2000-2003	Consultations in previous year ^a
Dick	Rents	Angina, anxiety, depression, asthma, hypertension, liver problems, hernia, cataracts	High 12 (12)
Jim	Rents	Disc injury, kidney problems, depression, arthritis, hypertension, penicillin allergy	High 8 (12)
Ian	Owens	Asthma, sore stomach, abdominal hernia, hypertension, angina, two heart attacks, spondylitis, back pain, worn discs	High 10 (8)
Rick	Owens	Osteoarthritis, depression, anxiety, bronchitis, heart murmur, pins and needles in both hands, alcohol problems	High 9 (5)
Roger	Owens	Depression, disc problem, hypertension, high cholesterol, anxiety, osteoarthritis, migraine	High 12 (5)
Janet	Rents	Asthma, hypertension, diabetes, osteoporosis, blood clots, anxiety, depression	High 12 (12)
Barbara	Rents	Hypertension, angina, two heart attacks, depression	High 12 (4)
Betty	Rents	Depression, irritable bowel syndrome, sinus problems, sciatica, ovarian cyst, migraine, tinnitus	High 12 (12)
Louise	Owens	Cystitis, arthritis, depression, breast cancer	High (8)
Lesley	Owens	Hypertension, asthma, colitis, duodenal ulcer, thyroid problems, anxiety, depression	High 20 (20)
June	Owens	Emphysema, angina, asthma, hypertension	High 16 (12)
Tommy	Rents	Ulcerative colitis, arthritis, gastric problems, hypertension	Low 3 (12)
Derek	Rents	Diabetes, depression, schizophrenia, peptic ulcer, hiatus hernia	Low 3 (3)
Johnny	Owens	Diabetes, kidney problems, hypertension, depression, alcohol problems	Low 2 (2)
Paul	Owens	Mechanical back pain, joint pain, photosensitivity, stomach problems, hay fever	Low 3 (3)
Peter	Owens	Proctectomy and ileostomy, pelvic abscess, asthma, eczema	Low 2 (3)
Sarah	Rents	Irritable bowel syndrome, migraine, hypertension, inner ear problems	Low 1 (2)
Mary	Rents	Osteoarthritis, partial deafness, gastric ulcer, sinus trouble	Low 3 (2)
Martha	Rents	Hypertension, collapsed lumbar disc, osteoarthritis, longsightedness	Low 1 (2)
Jane	Owens	Stress, anxiety, oesophageal reflex, numbness in right hand, back pain, patchy keratosis	Low 1 (2)
Marie	Owens	Myalgic encephalitis, cyst on thyroid gland, palpitations,, allergy to dust	Low 2 (1)
Susan	Owens	Depression, irritable bowel syndrome, sinusitis, hay fever	Low 2 (6)
Rita	Owens	Breast cancer, anxiety, depression, panic attacks, gastric ulcer	Low 1 (1)

^aNumber of consultations reported in previous year at wave 4 of Twenty-07 study. On the basis of this, those with seven or more were classified as 'high' consulters and those with three or fewer as 'low' consulters. Second figure, in parentheses: consultations reported in previous year at study interview (2001-2002).

strike a balance between facilitating talk that would generate 'rich' data, framing questions in a sensitive way, and not pursuing issues that were clearly upsetting. Confidentiality was assured, and pseudonyms are used throughout.

Analysis

The transcripts were checked for accuracy against tape recordings. The analysis was based on the constant-comparison method, and informed by a narrative approach. This allowed a systematic and rigorous analysis, which looked for coherence and consistency between and within transcripts, and attended to the 'moral point' of accounts.³¹ Following Agar and Hobbs (in Riessman),³¹ three levels of coherence were sought. Global coherence referred to what the speaker was attempting to achieve overall (e.g. construction of a coherent moral self); local coherence referred to the rhetorical devices employed to attain the overall goal (e.g. positioning of oneself alongside others in the account); themal coherence referred to the content of the account (e.g. actions taken to manage illness in daily life). All passages of text were read and annotated line by line, paragraphs were categorized in broad-brush ways, and preliminary themes were identified.

Early in this process, several transcripts were read by all authors independently to identify major themes. Themes were revised after discussion and repeated reading of transcripts, and were explored for consistency within and between accounts. Some themes relating to the practices of self-management were identified at an early stage of the analysis. Others (such as the prioritization of maintaining social roles and the management of identity) only emerged with further analysis. Once a theme had emerged explicitly from some interviews, the data were re-analysed to establish whether other transcripts referred to the theme explicitly or implicitly, and to look for deviant cases to develop and refine the findings.

This approach allowed constant comparisons to be made on the three levels of coherence. The software package nVivo allowed revisits to large sections of text, avoiding fragmentation as far as possible.

RESULTS

Managing Symptoms

Typically, participants expressed frustrations around their symptoms, and the impact of illness on their daily lives, conveying a moral obligation, or responsibility, to manage their symptoms alongside daily life 'well'. For example, individuals said things such as the following:

If it's not one thing it's another. I wake up and say 'What is it today?' ... It restricts me terrible ... I feel like my life is coming to an end with emphysema and I know it shouldn't. (Lesley)

I just seem to go to bed, sleep, get up, watch the television and vegetate. And I know I shouldn't be doing that. (Betty)

I know myself personally I should be doing that [going out], but I can't do it. (Dick)

Here the participants identify what *should* and *should not* occur in terms of symptoms, activities and daily life, illustrating that particular responses to symptoms are value-laden, and managing symptoms alongside daily life is a moral activity. An inability to contain symptoms was a common concern, and suggests an added burden on those who display an inability to function in ways that are culturally valued.

The accounts featured concerns around the ability to carry out daily tasks, and attempts to maintain familiar activities and a sense of continuity with past lives, and 'former selves'. The participants discussed using multiple techniques in their attempts to manage symptoms alongside daily life. They described pacing, talking to others, medication, the use of formal services, and support from social networks such as friends, family and work colleagues. For example, comments included the following:

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Researcher: *So what do you think is the most crucial thing in helping you manage your symptoms?*

Rita: *I don't know, I just try and get on with it and I phone my pal and I blether. If she knows I am down in the dumps she'll phone me and she'll phone me back an hour later. She always comes up with something funny, you know, to take your mind off things.*

You pace yourself through the day, you know... If I'm hoovering, I have to shift the settee and what have you. I'll maybe be doing half the floor and sit down, have a rest, have a cigarette, shift the settee and get up and do the other bit. You know, sit and move the furniture and do the rest of it. (Jim)

The above extracts illustrate common themes that emerged in the analysis: the ongoing process of managing symptoms (Rita), and daily life (Jim). However, as participants conveyed the significance of maintaining favoured social roles and identities, they revealed the tensions and ambiguities that permeate the chronic illness experience.

Managing and Maintaining Valued Social Roles

Participants described how they negotiated symptoms, symptom management and valued social roles such as 'being a worker' or 'being a mum'.

Being a worker

Many of the participants talked about the importance of paid employment in their daily lives. Some considered being unemployed as a sense of loss, and described how their illness had caused them to leave paid work. Others revealed employment as a helpful management strategy *in spite of* potential risks to health. Martha experienced debilitating pain in her back and legs and commented:

People... they say that I work too much... but it's not like that at all, it's completely different from that. If I did not have that [work] what, what would I be, just sitting here and that's it. (Martha)

Individuals adopted a range of coping strategies, including pacing, resting, medication, and equipment use, in their attempts to remain in, or return to, employment. They

revealed the hard work that this entailed. For instance, pacing was not just a practical endeavour, but was conveyed as a moral activity, which facilitated employment, and as such affirmed people as members of a moral community. In this way, the practical problems of the body are linked to one's sense of self, and one's place in society:

I get up and get washed and have breakfast and then I get dressed... This morning I went upstairs and the next thing I knew I lay down on the bed for about between 10 and 15 minutes because I felt tired, because of the hassle of getting up, getting ready... I just had to lie down... And then you kind of force yourself, otherwise, I think I would be tempted to, you know, just take codeine and go to bed. It's that sort of fine line, I'll have a wee lie down for 5 or 10 minutes and then I'll get up and go, no matter what. Otherwise I could sort of spend the morning in bed... but you can't, you know... I'm just kind of a law-abiding person and I obey the rules. And I know you're supposed to go to work, and it's unfair if you don't go to work, so I just do it... That's my East end of Glasgow upbringing which does that, it's a good protestant work ethic. (Peter)

Both men and women who remained in employment conveyed that being employed was important for their identities. The desire to function in social roles, and maintain familiar lives and selves, drove action. Participants spoke of not 'giving in' to illness. An inability to be employed, or fulfil other social roles and obligations, was seen as a form of failure that threatened coherent identities. The participants faced moral concerns as they tried to be 'responsible' patients, living 'normal' lives. The ability to manage illness alongside social obligations in daily life was framed as a sense of duty. While the men who were employed tended to construct their masculine identities in terms of traditional male providers, the employed women conveyed their employment status as an important part of their identities as independent women, separate from their domestic role. This will be discussed further elsewhere.

Being a mum

The ability to fulfil familiar roles and maintain favoured identities had both practical

and symbolic value. If the participants could accomplish 'normal' life, they could illustrate a level of control over their illness and their bodies, and establish their moral adequacy. The women's accounts featured how they reflexively negotiated illness and daily life, but highlighted how they fostered actions that reaffirmed them as mothers (and grandmothers). At times, they described careful monitoring and complex self-management strategies, consciously doing things that would potentially harm their vulnerable bodies, and escalate illness:

If I get too tired it [newly diagnosed multiple sclerosis] gets worse ... once I've lost it I'll never regain it [fitness] ... that's how I know I'm being daft when I say 'Bugger it! I'm just going to carry on.' And it's, most times I think I'm sensible but sometimes I just think to myself 'Och', you know, 'Rebel'. I want to rebel ... I'm fed up I want to shout, I want to scream ... My doctor tells me not to struggle on but I still do try and struggle on because I feel that I'm independent and I don't want to lose that independence. Although I can feel absolutely rotten, I'm not going to wait on someone giving me a cup of tea. I'll get up and grab onto the walls using my stick and make a cup of tea for myself, and feeling absolutely ghastly ... trying to make life as normal as possible ... It's like a mum thing, a mother thing, a woman thing ... it's very hard for me to turn and just say 'Right, okay, I feel lousy, I'm just going to sit where I am.' And I don't think I'll be the only woman that does that ... trying to make life as normal as possible.
(Betty)

This common theme is clearly articulated by Betty. Her account features how she strives to undertake actions in the domestic sphere, and in so doing, risks aggravating her illness. However, in the context of a daily life that has been diminished by illness, she gains a sense of independence, maintaining aspects of her familiar self in her attempt to keep life as 'normal' as possible. She reaffirms her identity as a mother, by drawing on shared cultural assumptions and positioning herself in a community of women. There is a common-sense understanding that 'being a mum' trumps being a 'good patient'. This underlines the ways in which symptom management, social roles and familiar identities are inextricably linked, and morally

infused. Janet, who noted rheumatoid arthritis in study interview alongside other health conditions, mirrors Betty's experience:

I tend to overdo it sometimes and I suffer badly for it as well ... like, say, my daughter's moving house there, giving her a hand recently, we were doing cleaning of the place and I suffered for about three days after it ... I was in absolute agony, agony ... the doctor gave me painkillers ... But at the end of the day, it's your daughter and you do it and that's it, it's your family ... The illness comes secondary to your family, as you'll probably know being a mother yourself, and it always will be ... I'll be honest ... I would do it again. No point in lying to you. (Janet)

The female participants drew on common-sense assumptions about their traditional family roles, paralleling the ways in which the male participants talked about their role as family providers. It would be misleading to interpret this as a sign of clearly demarcated gender roles in the family. However, such talk does indicate that self-management is a complex process, grounded in the particular context of the everyday, but also permeated by social and cultural factors. As they spoke, the men and women drew on cultural assumptions of idealized masculine and feminine behaviours. This had implications for how they constructed their moral worth in the accounts, and also suggests that illness management work is practical and emotional, and informed by moral guidelines. This gendered aspect of the accounts will be discussed in detail elsewhere.

'Being normal' and favoured self-image

Some of the participants discussed using equipment to ease symptoms and aid functioning. While equipment could be constructed as a resource, e.g. to help maintain paid employment, it could also be seen as a symbol of illness and premature ageing that could threaten identity. It was less likely to be seen as a resource when it had negative connotations, and fundamentally clashed with an individual's self-image:

I just don't want to be seen walking about with a walking stick. I would rather limp ... it's just a sign of getting old and I don't want to be there. My memories of old guys with walking sticks, you know the sort of cloth cap,

walking stick and maybe a watch around the side and he's chasing you and can't catch you and hits you with a stick or throws it at you. I don't want to go there. I should use it, but I have an image of an old man in a cap and a waistcoat, shouting at us kids. (Rick)

In a bid to accommodate symptoms and function 'normally', people were willing to endure discomfort. The need to resist disruption and live 'normally' overrode distressing symptoms. Overall, people attempted to 'keep up appearances', struggle with symptoms, and emphasize their healthy status through normal activities. June describes a struggle to resist disruption of a 'normal' life-course trajectory. The equipment to which she refers offers potential relief, but is also a tangible symbol of chronic illness and ageing:

I'm struggling with the stairs. When I come down in the morning I dread having to go back up to the toilet, I dread it ... Once I was tempted to go over and ask them about a toilet downstairs ... I'd like to move. To get away from the stairs, and yet, if I move I'm giving in. I feel as if you're not disabled yet and you're not going to be, so don't think along those lines. I don't want to think along those lines. I'm too young. I mean it's ridiculous. Fifty-two, you know, at 52, to think of stair lifts and toilets downstairs, do you know what I mean? (June)

Others justified their decision not to attend support and rehabilitation groups by saying that their self-image clashed with such attendance. However, they were able to justify their decisions, by, for example, noting independent self-management strategies:

The stroke resources ... they deal with people in there, the stroke victims ... they [stroke support workers] actually want me to go tomorrow, but I was thinking about it and then I'd been in the other morning there ... and I looked and it was all old folk and it's discussion groups and I really think that if I sat with old folks I would end up, it would depress me ... I am trying to get on myself, because I go to the swimming every morning. (Tommy)

The ambivalences that these people with multiple morbidity expressed regarding the use of medication to manage their symptoms are discussed elsewhere,²⁴ but medication use was also linked to self-image. Participants aligned resisting symptomatic medication with maintaining control over the body, over symptoms and over one's identity.

Antidepressants, in particular, were resisted when associated with negative self-image. However, if congruent with a more favourable identity, they were more likely to be regarded as a self-management tool. Louise gave an extensive account of why she initially refused her general practitioner's advice to take antidepressants; however, when she later framed depression as a chemical imbalance, and thus felt no longer culpable, she felt able to use them as a resource:

I ... didn't accept it [being prescribed antidepressants] before ... Because I always felt it was my fault, 'I'm not a very nice person' ... if you're suffering from diabetes, you need to go and get your insulin ... if you can't see properly, you need glasses. If you've got a chemical imbalance, you need antidepressants. And it was like, 'Yes, yes, this is it.' It was just like a revelation. (Louise)

The accounts revealed that if strategies to manage symptoms clashed with a sense of a familiar self, they might be rejected in favour of behaviours that bolstered a 'normal' life and coherent identity. However, views could change over time, and as the above extract illustrates, if a positive sense of self can be maintained, then resources are more likely to be used.

DISCUSSION

Participants in this study, all experiencing multiple chronic illnesses, in their early fifties, described their attempts to manage or control their symptoms 'well', expressed as something they knew they *should* do. However, in the context of a world that was diminished and disrupted by their illness, they also felt compelled to control particular aspects of daily life, and in particular fulfil social roles and obligations (e.g. paid work and parenting). The way in which participants spoke demonstrated that self-management of their symptoms was essentially core *moral work* intertwined with maintaining some semblance of a coherent and positive identity. Yet the priority given

to 'identity' management was sometimes said to be at the cost of their symptom management; there was a mismatch between controlling symptoms and maintaining control over their social roles, sense of normality and moral identities.

The scope of the study was limited by constraints imposed by the larger study used as the sampling frame, including its geographical location. The issues raised may have been particularly salient to people living in west central Scotland, and to those experiencing multiple morbidity early in midlife. Younger or older people may respond differently. However, the strength of the study lies in its in-depth analysis of individuals' accounts, and the findings build on research with people with a single chronic illness in other parts of the UK and internationally.

The qualitative data collected in this study reinforce existing evidence about the complex experience of chronic illness. They highlight the common recurring dilemmas that individuals face as they strive to contain symptoms, live normal lives, and maintain coherent identities. Previous research has demonstrated the practical^{4,6,7,15} and existential^{6,7,9,15} difficulties faced by people with chronic illness. Overall, the findings further illustrate how functional problems and attempts to limit them are anchored in everyday life, informed by a broader cultural context. The ongoing, reflexive and moral work of self-management is revealed. Illness management is a multidimensional process, involving a complex interplay of the personal, cultural and social circumstances of illness.

Building on work that has pinpointed the moral dimension of illness,^{14,26} this paper has suggested that the imperative to manage ongoing illness well is moral work undertaken in daily life. This moral work extends beyond the medical encounter²³ and the ability to control symptoms with a positive attitude.²¹ The personal and routine behaviours linked explicitly to bodily function are conceived as moral imperatives. Participants spoke of their desire to act as

one 'should' in the face of debilitating symptoms. For example, accounts conveyed the need to fulfil 'the work ethic', and to perform domestic tasks as 'a mother', despite risking pain, and resistance to being seen, or seeing oneself, as 'old' or simply 'not a very nice person'. Such talk reveals how individual experience of the body, and how one manages it, is guided by normative values, and highlights the dilemmas of the moral agent. The ability to 'get on with it', i.e. manage symptoms, function in routine ways, undertake tasks and fulfil roles, is prioritized.

This paper further highlights the daily tensions and ambivalence that contribute to the complexity of the chronic illness experience, and pervade self-management. Conceptualizing the moral dimension as a line of work draws on previous research, particularly that of Corbin and Strauss,¹⁹ and adds insight into the interconnected and fluid practical and moral dimensions of chronic illness. The process of self-management could be eased if the particular circumstances, and the broader social and cultural context in which it takes place, are addressed, and the subsequent nature and extent of different types of practical and moral work are considered by policies, programmes and practitioners.

The findings suggest that it would be helpful to those experiencing such tension if self-management policies and health professionals could recognize the concerns and priorities of those with chronic illness. Controlling symptoms may not always be their main priority in the face of threats to valued social roles, identities and a 'normal life'. A comprehensive understanding of how people negotiate symptoms, symptom management and daily life as practical, emotional *and* moral work is called for; this would benefit patients' self-management programme outcomes.

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