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Misery loves company: Identifying factors influencing cognitions of self-care for patients living with long term conditions

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Abstract
Prevalence rates for Long Term Conditions are increasing in the UK. Research suggests a strong association between physical health, mental health and treatment outcome. As part of NICE (2009) and DoH (2012) guidelines for managing LTCs, patient participation and self- care is core to the success of treatment for LTC. Poor adherence to treatment regimens by patients has resulted in excess expenditure and time by services attempting to identify and manage barriers to this problem. Inherent in this process is consideration of those wider factors that influence concepts and cognitions of self-care and supporting patients to understand how these impacts on motivation to change, thus improving not only treatment outcomes but also reduce valuable health care consumption.

Keywords: Long term conditions; Self-care in health; Treatment adherence; Long term cognitions

1. Introduction

"...and things are getting bad again. but sometimes
there are more practical things to consider
like co-pays and insurance companies. I stay in bed.
if only things would hurt in a clearer way." - Chronic Illness by Fortessa Latfif

These Long term conditions (LTC) are defined as those diseases which at present, cannot be cured and are managed through medication and secondary therapies which focus on wider dietary and lifestyle changes. LTC cover a range of illnesses including diabetes, respiratory disease, coronary heart disease as well as dementia, cancer and stroke amongst others. Included under LTC is not only mental illness but also a diagnosis of depression (DoH, 2012). Research has found there to be a strong link between increased risk and co-morbidity of LTC and mental health issues - in prevalence as well as treatment outcomes. In the UK, the resultant health service consumption of this population has led to the rolling out of IAPT (Improved Access to Psychological Therapy) services and specialist LTC psychology services in order to allow all presentations within LTCs to be supported (NICE 2009).

According to a Kings Fund Study (2022) approximately 15 million people in England are living with a LTC with increased prevalence rates in older people and in more deprived socioeconomic groups, with projected rates increasing with a growing population of older adults.

Central to many of the UK NICE recommendations for LTC services is the idea of increased patient self-care. Whilst the recognition of the interplay between physical and mental health has been of significance, the context of self-care centres on its relationships to the LTC. However, concepts of self-care do not exist solely around physical illness but evolve throughout our lives and are dependent on our life experiences. It is the way in which patients manage their (significant) life events that impacts on their capacity to take responsibility and thus enable them to be active in their self-care whatever the context. In order to understand self-care in the context of LTC we must necessarily understand the factors that shape it.

As the poem above demonstrates life events (be they significant or daily stressors) influence our attitudes and motivation towards the prioritization of our health. Our learning often stems from unhappy, distressing and traumatic experiences which often result in the development of unhealthy/negative beliefs around self-esteem/worth/value. These beliefs further affect beliefs around locus of control for change, levels of personal responsibility and motivation to change. The coping strategies employed by patients in these situations often involve unhealthy comfort seeking behaviours (i.e., comfort food, smoking/drinking/long periods of inactivity in bed or watching television, isolation etc - especially when physical health creates its own physical limitations) thus causing further problems with their condition. We see then, how negative cognitions stemming from life events impacts on the maintenance of not only unhealthy behaviours but also on patient attitudes to self-care as a whole. This can lead many LTC patients to be stuck in a vicious cycle, and the impact of this chain of events upon treatment adherence and poor outcomes is self-evident.

Whilst research acknowledges the broader association between mental and physical health, the aim of this paper is to build on this knowledge with case examples to highlight the wider influences upon the development of patterns which cause barriers to patients' self-care. The paper also aims to raise awareness of the relevance of considering the impact of those life events and experiences, which may appear to be irrelevant to our professional management of LTCs but in fact are directly influential on the way our patients manage their condition. Since there is little direct research in this area examples are drawn from practice-based evidence and experiences with this population. The author is an experienced health psychologist and refers to patient presentations and patterns of behaviour in her extensive clinical work with this population.

1.1. LTC prevalence rates

In the UK, since most specialist psychology services for LTC centre on diabetes, CHD and respiratory disease (as distinct from secondary health psychology services), prevalence data is specific to these three areas. Psychology services for other LTCs such as stroke, cancer cardiac rehabilitation are offered as individual services. Prevalence figures show not only increasing numbers of LTC diagnoses but highlight trends regarding gender, ethnicity and age.

1.2. Diabetes

According to Public Health England (2016) approximately 3.8 million people aged 16 years and over in England had diabetes (diagnosed and undiagnosed). Statistics showed that prevalence was higher in accordance with gender (men -9.6% and women- 7.6%) and ethnicity (South Asian, black ethnic groups 15.2% and white, mixed or other, ethnic groups- 8.0%). Further, there is a clear association between increasing age and higher diabetes prevalence, from 9.0% aged 45 to 54 to 23.8% aged 75 years and over. The survey predicted that diabetes prevalence was expected to increase to 4.9 million or 9.7% by 2035.

1.3. Respiratory disease

Statista (England: Respiratory illness among older people 2018/19 | Statista) found that approximately 12.7 million people in the UK (i.e., 1 in 5) have a history of asthma, COPD or another longstanding respiratory illness. Estimates based on GP records suggest that 8 million people have been diagnosed with asthma, 1.2 million with COPD, and over 150,000 with interstitial lung diseases (pulmonary fibrosis or sarcoidosis), with a further 86,000 people in the UK estimated to have been diagnosed with lung cancer. Whilst statistics showed there was a growing trend towards men having the higher mortality rates with some regional gender differences in the North of England, when age was

factored in 16.3 percent of women aged over 80 years were living with a respiratory illness compared to 13.1 percent of men in the same age group.

1.4. Coronary heart disease (CHD)

According to the British Heart Foundation (BHF UK CVD Factsheet) CHD is the one of the UK's leading causes of death and the most common cause of premature death, responsible for around 64,000 deaths in the UK each year, with 1/8 men, and 1/15 women dying from CHD. Under the wider umbrella of cardiovascular disease (of which CHD is one diagnosis) statistics show that the aging and elderly population are particularly susceptible to cardiovascular disease although these risks are compounded by additional factors, including frailty, obesity, and diabetes.

1.5. Links between LTC and mental health problems

Mental illness is in and of itself, identified as a LTC as is a diagnosis of depression (DoH, 2012). Research demonstrates that there is a strong association between physical illness and mental health problems. For example, people with a primary LTC such as diabetes, hypertension and CHD have double the rate of mental illness and patients with a primary diagnosis of COPD, cerebrovascular disease and other chronic illnesses have triple the rate. Patients with multi-morbidities within LTC are seven times more likely to suffer from depression. Research also found that people with a primary mental health diagnosis of schizophrenia, bi-polar, depression and anxiety were all more likely to develop LTCs such as diabetes or CHD.

In terms of treatment outcomes, research has consistently shown that untreated mental health problems for patients with LTC are more likely to lead to a poor health outcome as well increased risk of further illness, even resulting in higher mortality rates (Bhat, 2020; Kalra et al, 2018; Pumar et al, 2014; Cafarella et al, 2012; Frasure-Smith et al, 2009; Simon, 2005; Nemeroff, 2000; Lesperance and Frasure-Smith et al, 1999; Carney, 1988 and Rozanski, 1988)

We see then that age is one of three key risk factors within the context of not only physical but mental health conditions. In UK LTC psychology services, patients are in the most part older adults -65. This is of relevance when we consider the natural partnerships between ageing and (unresolved) life events/experiences as well as older generational attitudes towards identifying/addressing psychological problems and diagnosis -which have only more recently become part of the consciousness of younger generations in the UK. Therefore, we see then the relevance of considering the impact of life events on concepts of self-care, given the influence on the patient presentations in LTC services.

2. Method

2.1. Methodological consideration

The relationship between mental health and treatment adherence. Whilst statistics give us a valuable picture of prevalence and relationships between mental and physical health, there is very little research on the relationship between the impact of mental health on adherence to LTC treatment adherence and outcomes.

There appear to be only two research studies in this area, both carried out by the Dawn Study Group (2013 and 2005). These studies explored not only psychosocial outcomes of people living with LTC but also barriers to treatment outcome - where mental health problems were identified as contributing factors. Results demonstrated that that adherence to treatment was poor, especially for diet and exercise regimens, with patients not fully recognising their own levels of self-care. Whilst diabetes-related worries were common, 41% of patients had poor psychological well-being and although it was recognised that psychological problems affected self-care, fewer than 10% of patients reported receiving relevant interventions.

The research was significant in highlighting the role and influence of the concept of self-care on treatment outcome. However, beyond this, there has been no further information on the importance of resolution of those experiences which influence cognitions of self-care; a concept central to management of LTCs.

2.2. Links to specialist LTC psychological services

In UK specialist LTC psychology services, patients are initially triaged and assessed for issues related to LTC, risk and/or those mental health issues which pre-date or are directly unrelated to health concerns. In the former case, patients are seen under LTC services and in the latter case they are generally referred primarily to IAPT or secondary mental health services in order to stabilise mental health and facilitate the effectiveness any subsequent LTC service intervention. (On occasion psychology services may consult with psychiatric nursing colleagues but never in the context of offering two parallel forms of psychological therapy).

2.3. Therapeutical considerations

Whilst the research tells us that mental and physical health are connected, the 'split' in healthcare services means that this message may not be clearly conveyed to our patients. Services are of course restricted by funds and staffing as well as extremely long waiting lists and as such do not have the luxury to deal with both aspects of the illness and offer extended therapy sessions. This leaves therapists in LTC settings to dissect those aspects of the mental health diagnoses that impact on self-care in general and those that affect the LTC which influence treatment adherence. Relevant issues tend then to be referred to individual services with little room to consider any conceptual overlap. This neither allows the patient to acknowledge/identify nor to integrate the impact of life experiences and events on the way in which they manage ill health- unhelpfully suggesting that the two as disconnected. Even if we are to accept that certain mental health problems may not be overtly connected to LTC management - the resultant cognitions around self-care developed from generic life events mean that wider life events cannot be ignored.

Both LTC patients and healthcare staff are exposed to this 'problem-splitting', and it is a gap which they must necessarily bridge across professions and teams to create a clear treatment plan. Specialist LTC psychology services are best placed to highlight the connection not only by their intervention but also in their raising awareness of its impacts on treatment adherence and outcome.

3. Results and Discussions

3.1. A case example and problem formulation

Our clinical experience in therapy tells us that when implementing psychological interventions, it is these very life events and not necessarily attitudes towards illness itself that can cause significant obstacles to treatment adherence due to the resultant underlying beliefs around external loci of control and an absence of awareness around personal responsibility for self-care and health maintenance.

Practice-based evidence has repeatedly demonstrated that patients are less likely to prioritise ill health issues in instances where they are living with unresolved life events/on-going life stressors. Comfort seeking behaviours employed to manage life stress are often in direct contradiction to treatment regimens and as such patients often choose to prioritise immediate comfort at the expense of long-term health issues - which are held off until the there is a concern of serious risk.

The key to understanding this can help shift patient motivation regarding not only physical and mental health problems but subsequently treatment outcomes, benefiting both patients and healthcare service consumption. Although the case below is a patient with Type 1 diabetes, the issues below have been noted to be commonly present across the above mentioned LTCs.

Following is a case example illustrating how life events impact on concepts of self-care and in turn impact on treatment adherence (Details have been changed to avoid recognition). The case describes the experience of a 69-year-old white-ethnic, femal, Dorothy, referred to the LTC psychology service. Following an initial psychological assessment, the following problem formulation was presented to Dorothy:

1. Presenting problem (reason for referral)
    - Poor treatment adherence for type 1 diabetes treatment re-diet/blood sugar checks/administering insulin. Dorothy felt well informed by her GP who had raised these concerns with the LTC team.

2. Predisposing factors (physical and psychosocial)

- Dorothy had a diagnosis of global degenerative arthritis. She also suffered with ill-fitting dentures which meant that she struggled to eat food. She had not seen her dentists or dietitian for two years due to the covid pandemic delays in healthcare.
- Dorothy had numerous undiagnosed health investigations on-going (Cardiac/Oncological in nature)
- She had pre-existing diagnoses of both anxiety and depression (20 years). This had not been treated historically but Dorothy had recently been offered anti-depressants with the onset of her recent Type 1 diagnosis being a trigger for her anxiety.
- Dorothy had also lived with symptoms of (undiagnosed) trauma as a result of being in a 'toxic' marriage for approximately thirty years, where she was psychologically abused by her partner who appeared to exhibit traits of a narcissistic personality disorder. Dorothy frequently suffered from anxiety, emotional distress, poor confidence and low motivation, inability to make decisions or take responsibility for life issues in general due to the level of control asserted over her by her husband. She had little awareness of the long-term effects the relationship had on her emotional or cognitive processes until our sessions.
- Dorothy had some unresolved issues around two bereavements (her father and aunt) where she had expressed concerns that she had not shown any distress in spite of the significance of these relationships.
- Due to multi-/co morbidity within LTC as well as mental health, Dorothy as an older adult from a low socioeconomic background was at overall greater risk of further health issues and poor treatment outcome.

3. Precipitating factors

- Dorothy had been advised by her GP and diabetes nurse that her poor treatment adherence would result in serious and increased risk to her health.
- Whilst Dorothy was aware of the seriousness of her situation, her numerous unresolved emotional issues meant that the treatment regimen was an additional stressor which left her feeling overwhelmed and as a result she sought comfort in food. Her ill -fitting dentures meant that certain foods were difficult to chew, as such she would take sweet drinks and chocolate and other soft food with high sugar/carbohydrate content (Cake/doughnuts/tea and biscuits etc). This allowed her to avoid adhering to treatment and fed in to her unhealth comfort seeking coping strategy. Dorothy felt stuck in this cycle but struggled with motivation to change.
- Dorothy has become concerned that she would not be able to care for her grandchildren or her mother which were her current priorities (see below)

4. Perpetuating factors

- Dorothy had an estranged relationship with two of her children and had little emotional support as she had been a single mother for the last twenty years. She had low self- esteem and motivation regarding forming new friendships and aside from her family, saw no one. Further, her experience of marriage had resulted in her avoiding further relationships with another partner. This resulted in increased isolation which was mitigated by offering all her spare time to her daughters' children with whom she spent a significant amount of time - babysitting.
- Dorothy's mother was suffering from a terminal illness. As the only child (both her sibling and father had died) she was the main carer for her mother who lived in another city which again resulted in underlying on-going stress with little respite time to address or prioritise her own needs.
- The isolation resulted in Dorothy ruminating on unhealthy beliefs that 'hers was not a life worth living' or 'her health not worth saving as she had nothing to look forward to' - feeding

into feelings of helplessness and poor motivation. She felt easily overwhelmed by having to take any decisions regarding her health as she had lived in a relationship where her husband had either taken all the decisions regarding her life and his or 'undone' any decisions she made independently. As such she felt it easier to simply avoid thinking about her LTC and focus on unhealthy comfort-seeking behaviours such as poor diet and staying at home watching Television- as a way of coping

- There were also generational issues regarding psychological management of life events. The patient reported that in her family/generation life events such as domestic problems were not seen as significant and as such any consequences were simply ignored. This meant that the resulting impact on her self-value/worth and esteem and so prioritisation of self-care regarding health was not considered as relevant.

5. Protective factors

- The lack of awareness of the danger of her behaviour was considered in the context of risk by neglect - albeit passive and not active in ideation or plan.
- There was no further risk of self-harm/suicidal ideation or plans as Dorothy's grandchildren's happiness was her main focus.

3.2. Psychological intervention

Psychological therapy began with consideration of the above formulation and exploration as to how the issues were not only manifest in beliefs about self -worth and value but also their connection to self-care and prioritisation of health. This enabled Dorothy to identify avoidance patterns and the link of her wider experiences on unhealthy comfort seeking behaviours. This itself helped Dorothy to understand influences as well as identify her capacity for motivation to change. Further work focused on Ego-Strengthening Hypnotherapy to improve emotional capacity and focus as well as identification of motivators for change and prioritisation of health concerns. Therapy also involved working on alternative comfort seeking behaviours and developing healthy cognitions when developing strategies to manage her LTC through Cognitive Behavioural Therapy (CBT). Upon completion, Dorothy requested referral to IPAT services to address remaining unresolved, bereavement issues.

Variations across gender and ethnicity and the specifics of life experiences mentioned notwithstanding, the above case is a common example of how life events, be they unhealthy relationships, traumatic incidents or generic life stresses, can influence the development of (un)healthy cognitions around self-value and so self-care.

4. Conclusion

Patients in LTC services present with a combination of physical and mental health issues. Whilst these aspects of the individual's life may be separated and referred to individual services, the interplay between factors contributing to cognitions related to self-care means they remain connected. Since self-care is central to treatment plans for managing LTC, it is important for all staff to be mindful of the above influences and patterns in order to offer patients a more comprehensive problem formulation and allow staff to more readily identify and consider potential barriers to treatment adherence. This in turn improving patient treatment outcome and reducing avoidable healthcare service consumption.

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