



## Responding to the existentials of non-life-threatening chronic conditions



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### ABSTRACT

Diagnosis of a major life-threatening illness can prompt a range of existential responses that typically include strong emotions and a reassessment of priorities. What has not attracted attention are the existential responses to being told about less major but permanent medical conditions. A conceptual frame is developed for identifying and speaking about the existential dynamics of permanent change. It introduces two key concepts, finitude and transcendence, and uses them to explain the common sequence of responses first from being told about a chronic condition through to when its presence has become integrated into everyday life. Based on this analysis, a range of recommendations are provided on what types of conversations are helpful through the various stages of adjustment.

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### Introduction

Twelve years have passed by since I was first diagnosed with celiac disease. It was news I did not wish to hear. Initially I was reluctant to take it on board, but I had little choice in the matter. A few months later a letter arrived from our Ministry of Health which stated, rather pointedly, that my condition would continue “for life”. I stared with foreboding at those two words, “for life”; they had an ominous ring; was it for real? Had they got the right person? Is this a life sentence? It was certainly not the sort of phrase I expected to read in a formal letter.

Celiac disease is not an earth-shattering condition. It does not lead necessarily to irreparable damage to the body and is fairly easy to manage by simply avoiding eating anything containing wheat, barley or rye. But despite this, it took me considerable time to get used to the idea of this chronic condition being part of my life. I remember one day, early on, I was walking through a large supermarket hunting out suitable food. Mounted up high on either side was aisle after aisle of breads, pastas, biscuits, pastries, cereals, sauces and canned and pre-prepared meals. The aisles seemed like canyons of gluten; tall walls of products closing around me and blocking me in; products with which I was fated to no longer have any relationship. I struggled to accept the existential dimensions of the permanency of this change.

In learning to accept and live with chronic health conditions, even relatively minor chronicities such as celiac disease or asthma,

a key part of the adaption has less to do with managing the condition and more to do with the reality of living with it as a permanent fixture. In other words, it is the ‘thatness’ or existential nature of the change that can pose a more significant challenge than the ‘whatness’ or the details regarding what to do about it. The existential nature of these transitions is easy to overlook, despite the key role it can play in how a condition becomes incorporated into a person’s life. The following paper presents a novel conceptual framework for thinking and speaking specifically about the existential dynamics involved in adjusting to chronic conditions.

### Recognising existentials

Before examining the existentials of chronic medical conditions, the following section introduces two concepts that are helpful in understanding the existential aspects of life situations.

#### *Finitude*

Finitude refers to here as all those aspects of our being that contain and frame us and hold us as finite. It incorporates the multiple ways in which each of us is confined within the corporeality of a particular body, constrained within the limits of space and time, contained within personal emotionality, framed within a particular outlook on the world and limited within the bounds of personal mortality [1–3]. As emphasised by leading existentialist thinkers such as Søren Kierkegaard [4], Martin Heidegger [5,6] and Paul Ricoeur [7], this situatedness of the self acts as a conditioning principle which structures all moments of human experience.

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Finitude is encountered in myriads of ways, at varying levels and in all aspects of everyday life. Sometimes we barely notice these moments passing: a fleeting and unnerving shiver down the spine, a nonspecific sense of unease or a momentary worry about the future. At other times finitude is encountered in an earth-shattering realisation which can shift our whole outlook on life, as occurs during near death experiences or major traffic accidents. In our mundane everyday situations, finitude tends to present itself as a vague awareness as we knock up against the bounded nature of our bodies, our minds and our personal attributes. These small events accumulate into something more potent; an experiential, almost visceral awareness that signals a stronger sense of boundedness which extends beyond any specific limitation [8,9]. This general awareness, in turn, is signalled and counter-signalled in symbolically meaningful moments such as an adolescent attending his first funeral, a woman realising her first symptoms of menopause signal the end of fertility and a middle-aged man seeing his greying hair as a sign of his inevitable decline in strength and stamina [10,11].

Individual existence, as given, is so structured that the self is only ever situated at one place and at one time; this situatedness is simply a condition for the reality of the self's individual presence [12,13]. Moreover, this situated self remains tied to a particular—and only one particular—abiding body. This condition of being-body-bound brings with it all the limitations associated with the physicality of the body: its fragility, its developmental changes, its deformities and its vulnerability to fatigue, to disease, to ageing, to hunger, to thirst, to heat, to cold and so forth [14]. A focus on the body-bounded nature of experience is fostering a rapidly expanding literature on “embodiment” [15,16]. However, this boundedness does not only pertain to the body. As individuals, our experience is conditioned by emotions, these in turn are conditioned by personal history, by cultural context and by personal tendencies and attributes. Interconnecting with these are a complex interplay between genetics and environment, an interplay currently attracting rising scientific interest in the field of epigenetics [17].

### *Transcendence*

Transcendence is a natural companion to finitude. It refers to those opportunities where human experience appears to move beyond its bounded, finite nature and connects with something that lies outside its own limitations. It functions as a counterbalance to all that bounds and limits personal reality.

Much of what we do involves attempts to engage with transcendence [18,19]. For example, the study of history and genealogy and other forms of storytelling are transcendental exercises in that they require tellers and listeners to move outside personal limitations of time and space, and, from a vantage point over and above one bounded individual, to look down at the progression of events over time. Similarly activities, such as portrait painting, taking photographs, writing autobiographies and erecting monuments, are often intended to extend a person's presence beyond his or her confinement to a particular time and place and perhaps to extend personal presence beyond a lifespan. Indeed, striving for transcendence can take on a large variety of forms from grand achievements (such as conquering mountains or landing on the moon) to personal triumphs (such as running marathons or overcoming the limitations of a disability) to connecting into other realms (such as communicating with the dead and meditating on a higher plane). Added to this, research into forms of transcendence or “self-transcendence” has led to promising applications in fields such as mental health, ageing and palliative care [20–22].

In many instances, striving for transcendence can involve such commitment that it ends up organising and framing daily routines.

For example, the marathon runner aiming to break her personal best is likely to plan her whole daily routine around fitness sessions, training runs and special dietary programmes. Other ways of seeking transcendence include trance and religious states, meditative states, alcohol and drug use and day-dreaming. The process of losing oneself in a particular activity is recognised as a key way of transcending circumstances, whether that be by means of a craft activity, a work project or attempting to win a competition. Another key form of transcendence occurs within our capacity for empathy for another person's circumstances. While we are each locked within our own inner worlds, we are still capable of imagining and constructing the inner worlds of others. This important form of transcendence is critical to our capacity to function socially [23,24].

### *Striving for a balance*

A key idea used in looking at how we adapt to change is to view the various parts of the systems we inhabit as constantly striving to maintain a point of balance, a state of “homeostases” – or, more flexibly, “allostasis” – where deviations are detected and effort is expended to re-establish order. In biology this idea is used to understand how body systems adapt to changing environments [25] and in psychology to understand the way we respond to stress [26]. It has also played a prominent role in the various schools of family therapy which view troubled behaviours by individual family members as attempts to restore a familiar and trusted balance back to a disrupted family system [27,28].

The idea of striving for balance can also help in describing the dynamic relationship between finitude and transcendence. The two push and pull against each other in our consciousness generating a tension that requires ongoing minor adjustments [29]. It is within this constant interplay that we seek to attain a balance. In normal circumstances, an increased sense of finitude might be compensated for by increased interest in opportunities for transcendence. However, there are circumstances when one side, either finitude or transcendence, gains such momentum and dominance in a person's life that a balance becomes difficult to achieve. Normal strategies for adjusting the balance do not appear to be effective and instead extreme measures appear the only option.

At times awareness of finitude can become so intense it effectively overshadows opportunities for transcendence. For example, a middle-aged administrator employed in the same office for fifteen years might have reached a stage where he experienced his work as increasingly constrained and hemmed in. On one particular day he sat down in his squeaky swivel chair, unpacked his bag and asked himself how he could possibly endure another fifteen years in this pokey little office. He is struck by the unbearable repetitiveness, the essential pointlessness of his mundane daily routines. He yearns for moments where he might step out of his bounded circumstances—to take off to a desert island, to have an affair, perhaps even to kill himself. But, for a variety of very understandable reasons, these radical strategies are not serious options.

At other times life can become over-imbued with transcendence. A young woman about to leave school is faced with an endless array of future careers. She lives in a home that will not be her home, she goes to a school that will have nothing to do with her future and she visits places, takes up interests and meets with people that she suspects will have little future relevance. She could become anyone, she could live anywhere in the world, she could adopt any lifestyle, she could shape her image and personality in any direction. She inhabits a transcendent, foggy world of endless potentialities and interacts with a long string of maybe-selves. She craves activities which might connect her to the rough edges of life; activities that make her feel raw and real.

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