Shame and diabetes self-management

Dr Alan Archer
MB BS, MA(Psych), FRCP, MD, Consultant General Physician Diabetologist (retired), and Humanistic Psychotherapist, Director Diabetes Counselling/Psychotherapy Unit, Nottingham City Hospital, Hucknall Road, Nottingham NG5 1PB, UK; email: alan.archer@nuh.nhs.uk

Correspondence to:
Dr Alan Archer, Humanistic Psychotherapist, Director Diabetes Counselling/Psychotherapy Unit, Dundee House, Nottingham City Hospital, Hucknall Road, Nottingham NG5 1PB, UK; email: alan.archer@nuh.nhs.uk

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Abstract
The central theme of this article is that a person with diabetes who thinks they are ‘not good enough’ at diabetes self-management is manifesting a sense of shame. This fundamental human attribute is often the most significant, underlying issue that people face in psychotherapy and yet neither the ICD-10 nor the DSM-V recognises shame as a discrete diagnosis.

In our diabetes consultations we have all experienced the person who speaks in self-deprecating tones about their high HbA1c level, how they are a ‘bad diabetic’, we sense, from their body language, that they think and feel ‘not good enough’ and expect to be criticised for poor glucose control. These are clues that tell us shame is present and, unless it is actively addressed, self-management is unlikely to deliver the healthy outcomes that the person with diabetes desires.

This article addresses what shame is, its purpose, how it develops, our response to it and how it may best be dealt with.

The language of psychotherapy is unlikely to be familiar to most diabetes health carers; I have therefore employed everyday language to present Humanistic psychotherapy shame concepts in as clear a way as possible.

The manner in which people with diabetes tackle, minute by minute, hour by hour and day in day out, their self-management is frequently shaped not only by their sense of personal shame but by how their diabetes carer’s own shame issues affect their consultation skills. Shame plays a major role in the eventual consequences of diabetes self-management.

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‘...the moments when something new has entered us, something unknown; our feelings grow mute in shy embarrassment, everything in us withdraws, a silence arises, and the new experience, which no one knows, stands in the midst of it all and says nothing.’

Rainer Maria Rilke

Introduction
As Rilke’s prose reminds us, shame is a ubiquitous, fundamental human attribute; medical and psychiatric literature rarely names it or discusses it in any detail. A recent search on the Cochrane Collaboration website gave two results out of 8093 records. In one paper shame was considered as a possibility following a diagnosis of genital warts, and the other quoted feelings of shame developing in women with female pattern hair loss. There were no reviews linking diabetes and shame. In mental health, shame is not given the status of a diagnosis.

Psychotherapists are well acquainted on a daily basis with how shame, until fairly recently, has remained socially hidden in the same way that death used to be taboo. Nathanson considers that shame has been treated as the ignored emotion, the Cinderella of the unpleasant emotions. He maintains that its importance lies in the fact that it is about the quality of the self.

On meeting people with diabetes for the first time in clinic, I invite them to tell me something about their diabetes. They usually reply, in a self-deprecating manner, ‘I’m a bad diabetic’, adding when invited to expand on this, ‘well I know my number [HbA1c] is too high, they keep telling me it is’—often said without eye contact, looking away at the ground, or out of the window; often without knowing what they mean by ‘bad diabetic’ or ‘my number.’ Thus, the tone of voice, facial expression and body language used by health professionals are sufficient to trigger a sense of not being good enough. This is shame and always has a negative effect on diabetes self-management.

So what is shame? Does it have a purpose? How does it develop? How do we respond to it? How is it best dealt with?

What is shame?
Shame, although easily recognised and felt, is not so easily defined. The ‘Oxford Dictionary of English’ describes it as, ‘a feeling of distress or
humiliation caused by consciousness of the guilt or folly of oneself or an associate.’ This confuses and equates guilt with shame; it speaks of shame being experienced at one remove through association with another.

Psychotherapy uses phenomenology (the study of consciousness and the objects of direct experience) to inquire into the nature of shame. Yontef says that shame is, ‘...the feeling of being “not OK” and/or “not enough”’... shame has a sense of defect or inferiority ... a sense of being unlovable and unworthy of respect ... carries the belief that with such a defect one does not truly belong in human company.’ Purton agrees that guilt may be induced by rule breaking but if, in addition, a person is threatened by, ‘since you are that sort of person I will go away’, they may feel shamed; a far greater, primal fear. Kaufman links shame with being seen in a painfully diminished sense. He says it is the shocked sense of the self exposed, the accompanying self-consciousness that is the essential characteristic of shame; he notes, ‘We stand revealed as lesser, painfully diminished in our own eyes and the eyes of others as well.’

Children’s fables often, at their kernel, describe the shame experience. Cinderella’s humiliation from sibling rivalry is the archetype of the genre. Internalised humiliation is also well recognised in ‘The Wind in the Willows’: the mole, ‘wet without and ashamed within’, follows his desperate attempts at rowing. Overt humiliation induced by a more powerful other is central in a Thomas the Tank Engine Tale when Gordon, a proud express train, shows off by rushing through a station. The Fat Controller demotes him by making him pull dirty coal trucks; Gordon responds with, ‘The shame of it, the shame of it, the shame of it.’

Shame is a felt-sense involving the loss of a portion of self, creating a raw wound and the self feeling degraded; to experience shame is to feel inherently bad, to feel fundamentally flawed compared to everyone else. Self-doubt sits like an incubus in the soul. Shame does not require others to be present. The gaze of an other can become internalised rendering the presence of that other unnecessary for shame to be experienced: ‘Only the self need watch the self and only the self need shame the self.’

**Does shame have a purpose?**

Freud considered shame, not a reaction against exhibitionistic/sexual drives, but a defence mechanism by which such drives are controlled. Nathanson has a more benign view of shame postulating that it might have a function as a ‘...monitor of interpersonal relatedness’. Broucek studied infants distressed with their inability to influence, predict or comprehend events, which previously they understood and controlled. He noted ‘...signs of distress in facial expressions, autonomic changes consisting of intensified respiration, increases in pulse rate, perspiration and blood flow to the skin’. He postulated these signs reflected primitive shame experiences in keeping with Tomkins’ Affect Thesis where shame is a mechanism for bringing about a reduction in the intensity of feelings in our basic emotional states – for instance, interest/excitement and enjoyment-joy. Thus, an infant of 10 months inspecting a shiny bracelet shows interest-excitement growing, being only able to control this dipole by tearing himself away from the object and ‘...covering his face with his hands and turning his head’. Kaufman views the role of ‘normal’ shame as something natural and necessary – playing a role in the development of conscience, motivating us to self-correction by ‘alerting us to misconduct or wrongdoing’.

**How does shame develop?**

Despite shame affecting the everyday functioning of the self, personality theorists have never given it the central status in the way that libido, sexuality, aggression and dependency are considered to be vital drivers to the construction of personality; and Kaufman is in no doubt that our relationships are forged in the ‘crucible of shame’. For the infant, parental non-verbal attuned responses are ‘ruled in’; while whatever evokes a parental averisive response is ‘ruled out’. Resultant cumulative responses determine infant behaviour; what they feel, want and think shape their current and future relationships. Children whose parents demonstrate the capacity to have experience and reflect on it (the skill of metacognitive monitoring) develop a healthy psychological integration of the balance between attachment and exploration, relatedness and self-definition. Such children when rated at 12 months of age for secure vs insecure attachment and, again, in adulthood show a 68–75% concordance. The more secure the attachments we develop as children, the greater the chance that as adults we will not think of ourselves being flawed and therefore vulnerable to shame.

In forging relationships we eventually experience that others want a relationship with us. Rogers described this as the bond of ‘positive reciprocal regard’, saying that ‘...it is rewarding both to satisfy this need in another, and to experience the satisfaction of one’s own need by another.’

Nathanson named this bond the ‘interpersonal bridge’, the facilitator of mutual understanding, growth and change. Developing this theme he said that: ‘whenever someone becomes significant to us, whenever another’s caring, respect or valuing matters, the possibility of generating shame emerges’ – the crucial, critical step occurring ‘when one significant person breaks the interpersonal bridge with the other’. For example, parental anger, rupturing the interpersonal bridge, may become nightmarish for a child if the parent fails to reaffirm the relationship, by providing touching and holding as the child reaches to be held.

Kaufman agrees that shame generation is preceded by relationship, adding that shame becomes ‘...internalised so that the self is able to activate shame without an inducing interpersonal event.’

Rogers regarded the desire for positive regard from a significant other to be so potent that it could become more compelling than the infant’s own self-valuing process. The message from others as to whether our experiences are worthy of their positive regard prompts us to select self-experiences as being either enhancing or demeaning to how we relate to our self and others. Rogers named this acquiring ‘conditions of worth’. The crucial stage in the acquisition of conditions of worth occurs when they are internalised: ‘by taking over the conceptions of others as our own, we lose contact with the potential wisdom or our own functioning, and lose confidence in ourselves.’

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**Review**

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Humanistic person-centred psychotherapists believe that throughout our lives introduction of conditions of worth from external authority figures, including how society expects us to behave, may encompass and weigh us down. The result is that we lead our lives flawed, ‘less than how we could be’. For some, their conditions of worth act to deny them the ability to navigate through life, resulting in profound unhappiness. Adherence to conditions of worth may prevent rupture of the interpersonal bridge but at the expense of being less than our potential, in a state of shame. People with diabetes have no problems reeling off conditions of worth: ‘don’t be too happy – bad things will happen’; ‘don’t be too clever – people won’t like you’; ‘take your insulin properly – otherwise you make me upset and I worry about you’; ‘you’ll go blind – if you don’t control your glucose properly’; ‘I know I’m a bad diabetic’. Diabetes health professionals are familiar with this endless list.

Shame originating in childhood can easily surface in adulthood. A woman enrolled on an intensive educational diabetes course emerged beaming with delight, saying that her new basal-bolus regimen had liberated her from the shackles of twice-daily insulin. She celebrated this with friends by dining out. During the meal, instead of the usual visit to the toilet to inject insulin, she injected fast-acting insulin using a pen device at the table. Twenty minutes later, two policemen entered the restaurant to question her in the light of another customer reporting seeing her injecting drugs. The officers quickly appreciated the truth, making a joke out of the incident. The woman experienced this as awful humiliation and then rising anger – not through a sense of injustice at being thought of as a drug addict, but through the fear of her sense of personal failure. The evening became a reminder of childhood injunctions constantly received from her father, ‘…you are too rooky, too cheeky for your own good; mark my words, you’ll come to a sticky end; anyway, who do you think you are?’

How do we respond to shame?
Shame is a common affliction that needs to be understood and acknowledged. It can be toxic and dangerous to experience directly and is generally experienced through our defensive response to its effects – the most common being the wearing of a frozen mask to prevent any hint of giving the game away, averted gaze and the head hung low.

I recently witnessed a doctor in discussion with a patient say, ‘Ah yes, you’re the diabetic, only to receive the riposte, ‘No, not a diabetic, but I do have diabetes.’ The doctor’s face froze briefly before regaining professional composure. He confided later how ashamed he felt using the word ‘diabetic’. I recall patients who, never having met me before, sit for a few minutes with the head-back look, perhaps implying that if they detect the slightest move on my part to shame them about their glucose control, ‘Watch out or I’ll shame you in return’. The head-back returned look and the sneer of contempt often work together to defend against overt shame. Secondary reactions masking shame from view include fear and distress of further exposure to being shamed, especially if any expression of shame is itself shaming. Rage can insulate the self from being wounded and an intensification of rage to hatred can actively keep others away.

People with diabetes are prone to experience shame when struggling to put into practice health professionals’ advice about practical aspects of diabetes care. This may include: discouragement, a form of temporary shame; self-consciousness, a form of self-mutilating shame; shyness, a form of self-consciousness, felt in the presence of strangers; embarrassment, socially inappropriate shame, experienced by many people when developing hypoglycaemia in public.

- Facial signs such as avoidance of eye contact, averting eyes, staring at the floor
- Affective signs such as embarrassment, self-consciousness
- Cognitive signs such as people describing themselves as a fraud, impostor and admitting to low self-esteem, empty inside and feeling different from other people
- Interpersonal signs designed to hide the self from scrutiny by others or often an attempt to control the situation

Box 1. Summary of Kaufman’s four indicators of shame

How do I know if someone with diabetes is experiencing shame?
The language of shame is often self-deprecatory, expressing a sense of inadequacy, being unworthy, not a joy to be with, defective in some basic way. Words used to describe shame include: not entitled, weak, humiliated, incompetent, inadequate, silly, stupid, dumb, exposed, never good enough. Some imagine they have to become the ‘ideal diabetes patient’ in order to please their diabetes team. They compare how far short they fall in blood glucose testing compared to how often they have been told to do it. The greater the discrepancy perceived, the greater the weight of shame to be dealt with.

Patients when confronted about high glucose values may experience growing anger, not due to any sense of injustice but fired by a sense of failure in their self-management. One potent result of constant negative judgements by some health carers is that any failure in self-management may become bound to a sense of shame, producing a diabetes-shame-bind that is activated whenever criticised.

We tend to praise people with ‘good’ levels of HbA1c as doing a good job of controlling their diabetes. Benign paternalistic statements like this may be an expression of our delight in how close the person is to our notion of the ‘ideal diabetic’. Patients with frequent hypoglycaemia often reveal a fear of falling short of being the ‘ideal patient’ – a fear kept at bay only by constant glucose checks. Perfectionism is their defence against the shame of not being an ‘ideal patient’. However, paradoxically, perfectionism by precipitating hypoglycaemia often hurls them into shame’s arms. Typical comments about hypoglycaus include: ‘I don’t want to be seen by others like that’; ‘People thought I was drunk and just stepped over me’; ‘I felt so small, so stupid’ – statements similar to Yontef’s that most people tipped into shame feel exposed … shame-oriented people project their own eyes [on to others] and expect to be found wanting. It is as if one’s own eyes are staring back … imagining that the others feel as much disgust as the self-disgust.’

Kaufman specifically identifies four indicators of shame (Box 1). The first, facial signs, are easily appreciated. Second are affective signs such as

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embarrassment, self-consciousness. The third, cognitive signs, includes people describing themselves as a fraud, impostor and admitting to low self-esteem, empty inside and feeling different from other people; Kaufman reports that when asked to clarify ‘different’ or ‘defective’, most resonate with the latter. In the fourth, interpersonal signs (so succinctly described by Milton in ‘Paradise Lost’ when Satan is banished to Hell, ‘...there they him laid, gnashing for anguish, despite and shame’) are designed to hide the self from scrutiny by others or often an attempt to control the situation. In the former camp sit denial of any issues, transfer of blame for poor diabetes management to others, gross perfectionism, and in the latter stormy exchanges and statements of contempt for health care; precipitating consultations so frustrating for health professionals, when for example it appears obvious that a patient is symptomatic from high glucose values.

I recently came across this example of defence against shame. A client of 38 years with newly diagnosed type 1 diabetes complained bitterly to her nurse that all advice about using insulin given by her was useless. From time to time she questioned whether the diagnosis was correct. The nurse found herself doubting her expertise and, feeling at a loss as to what to suggest next and, unusual for her, started to feel inadequate, that she was failing in her job. It transpired that the patient put great store in exercise and that she had been missing insulin injections in the belief that proper commitment to physical training would see off her diabetes. Deep down she was experiencing the shame of failing in her belief that it was her duty to maintain a healthy body. The nurse had fallen into the trap of a parallel process, well known to psychotherapists when a patient’s feelings of shame-failure are replicated in the health professional. The nurse’s upbringing had been peppered with the mantra, ‘...must always do your best – otherwise what will people think of you and the rest of the family?’

Shame may present as an eating issue. A patient with low weight recalled childhood meal times as being a battle field; forever being berated for being too full of beans, too impulsive, too noisy, too talkative, too keen on being heard and sometimes too quiet. The message she received was that her behaviour was flawed, socially incompetent and quite unacceptable. Mistakes were intolerable and she must learn to control herself. Sunday dinner could easily last 2 hours. She developed a sense of self-disgust, of being unworthy of social contact. Eating food became bound to self-disgust. This self-disgust-food-shame-bind could only be defended against by controlling food intake and appetite and, by wielding the power of choice, by missing insulin she could maintain strict control over her weight. At the same time she had a fear of personal failure with how she managed her diabetes. A great part of her therapy involved discovering insights linking food with her deep-seated self-disgust-shame and her failure as someone with poor diabetes self-management.

A psychotherapeutic approach to dealing with shame

Psychological support services for people with diabetes are in short supply. The National Service Framework for diabetes Standard 3, rationale 6 states: ‘...a diagnosis of diabetes can lead to poor psychological adjustment, including self-blame and denial, which can create barriers to effective self-management. The diagnosis can also create or reinforce a sense of low self-esteem and induce resistance and depression;’ and rationale 6 states: ‘The provision of information, education and psychological support that facilitates self-management is therefore the cornerstone of diabetes care.’

Yet the 2000 ABCD ‘Survey of consultant diabetologist-led services’ reported that ≤50% of diabetes units had access to psychological services. In part, to counter this, the Diabetes UK Professional Advisory Council has recommended that psychological well-being be assessed annually and that, ‘Diabetes healthcare professionals should be trained and supported to enable them to deliver emotional and psychological support themselves, at an appropriate level, with the aim of embedding this as an integral part of healthcare professional training for the future.’ If diabetes team members with good communication skills were able to deliver such a service then many more patients would be able to improve their self-management. Some patients with entrenched shame introjects might additionally benefit from a formal assessment with a counsellor/psychotherapist.

Diabetes carers and their patients all bring to consultations some degree of historical shame which has its nascence in childhood and the very least we as health carers must do is understand our own shame and not replay our patient’s shame scenarios by how we respond to their diabetes self-management. In any discussion of shame, self-consciousness, a form of internalised shame, is likely to be triggered in the inquirers causing them discomfort, but this should not deter us from being willing to work with our patients who have shame-based responses to their diabetes self-management. There is no place for sarcasm, teasing, pity, condescension; these can be devastating for someone
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prone to shame. It is crucial to remember that following the diagno-
sis the patient will be passing through all the developmental stages of their childhood as they tackle this new life project – diabetes. For some, self-
management is truly a Sisyphian task which, when hampered by the shame of not believing they are good enough, may seem impossible. When working with such patients I recall Arno57 who says that when ‘the boulder becomes too heavy, the burden overwhelming, I step in for a while and help shoulder the load.’ The message to themselves and the world at large that patients strive towards is, ‘what I am and what I feel are good enough.’36 People hobbled by shame are very often acutely sensi-
tive to non-verbal communication; facial body language in particular, such as a frown, a stare, a look away, may be interpreted as a form of con-
tempt. Health carers must not forget that the exchanges they have with their patients, ‘float on the stream of nonverbal communication… The drift of spoken dialogue – what is and is not addressed, and at what depth – is largely determined by the emotional and relational currents that flow beneath the surface of their interaction.’39

It is the client who knows what hurts, what directions to go, what problems are crucial, what experiences have been deeply buried.40 If diabetes carers are up to the chal-
lenge of supporting their patients in tackling shame they must provide a relationship in which the patient feels safe, secure and able to actively approach their shame issues, have them validated and allowed direct expression. Just as in childhood, the construction of an interpersonal bridge between patient and diabetes carer is essential to allow this mutual relationship to grow.

In any discussion of shame with patients, self-consciousness (a form of internalised shame) is likely to be triggered in the professional causing them discomfort. It may sound con-
troversial, but perhaps patients need to know that members of their dia-
betes team, whom they respect, also have feelings of shame, and may be willing to disclose them. I would rec-
ommend that diabetes health care professionals, who wish to be more authentic in their diabetes consulta-
tions, consider coming to terms with their own shame issues through sup-
portive, professional supervision. As a humanistic therapist, I believe that healing relationships are built upon Rogers’ core conditions41 of therapist congruence, empathy and unconditional positive regard for the client.

For Rogers, successful therapy is characterised by patients avoiding subjection (being forewarned of any experience threatening to the self), and moving away from deploying shame defences to prevent a trou-
bling stimulus from entering con-
sciousness.42 They can then accept themselves and their feelings more fully, become more self-confident, more the person they would like to be, more flexible, less rigid, and know when it is truly okay to healthily with-
draw the self from contact with others and adopt more realistic goals.42,43

Shame is at the core of shaping how we have become who we are. Therapy makes sense because to the self-management of diabetes is inestimable and so well reflected in WB Yeats’ words:44

I am content to follow to its source
Every event in action or in thought;
Measure the lot; forgive myself the lot!
When such as I cast out remorse
So great a sweetness flows into the breast
We must laugh and we must sing,
We are blest by everything.
Everything we look upon is blest.

**Declaration of interests**

There are no conflicts of interest declared.

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