Understanding barriers to medication adherence in people with diabetes

Jen Nash

Diabetes is one of the most psychologically and behaviourally demanding of the chronic medical illnesses (Cox and Gonder-Frederick, 1992). This can cause problems with adherence to recommended treatment, whether medication or healthy lifestyle choices. Haynes et al (2002) define adherence as the extent to which individuals follow the instructions they are given for prescribed treatments. This article defines and discusses adherence to medication in people with diabetes and outlines some factors which may influence a person's adherence to medication, including biological, cognitive, psychological and social factors. The author also provides some helpful ideas about how to discuss adherence in consultations.

Diabetes is one of the most psychologically and behaviourally demanding of the chronic medical illnesses (Cox and Gonder-Frederick, 1992), not least because 95% of the management of the condition is carried out by the person with diabetes themselves (Anderson, 1985). Non-adherence can be a costly issue in a number of ways; not only is it damaging to the individual's health outcomes, it is financially problematic due to increases in healthcare spending and higher use of unscheduled care.

This article will define adherence and describe the many factors that can influence it – biological, cognitive, psychological and social. Ideas will be shared about how clinicians can discuss adherence in their consultations with people with diabetes, with the aim of developing a collaborative approach to increasing motivation for adherence.

What is adherence?

Haynes et al (2002) define adherence as the extent to which individuals follow the instructions they are given for prescribed treatments. Literature investigating rates of adherence vary in their findings, in part because there are a number of domains of adherence, including medication use and lifestyle recommendations, such as diet and exercise. A person may be adherent to some aspects of their self-care regime but not others. It is important to note that adherence to medication is a very different issue to adherence to healthy lifestyle choices, with very different barriers. The large Diabetes Attitudes, Wishes and Needs (DAWN) study found that 83% of people with type 1 diabetes and 78% of people with type 2 diabetes self-reported that they adhere to medication. The self-reported adherence figures for self-monitoring of blood glucose were 70% and 64% respectively; for diet the figures were 39% and 37% respectively and for exercise the results were 37% and 35% respectively (Peyrot et al, 2005).

The term adherence is intended to be a non-judgemental, non-blaming term. It is a statement of fact rather than implying fault to the person with diabetes, treatment or prescribing clinician. It is, therefore, a better alternative to "compliance", which suggests the person has intentionally done something wrong. However, as professionals it is all too easy to use the

Citation: Nash J (2013) Understanding barriers to medication adherence in people with diabetes. *Journal of Diabetes Nursing* **17**: 263–7

Article points

1. Adherence has been defined as the extent to which individuals follow the instructions they are given for prescribed treatments (Haynes et al, 2002). The need for self-management in diabetes means that it is one of the most psychologically and behaviourally demanding long-term conditions.
2. Factors that may influence whether a person adheres to medication include biological factors, cognitive factors, psychological factors and social factors.
3. Multidisciplinary teams have consistently been shown to improve adherence outcomes (Nau, 2012). There is also evidence that the use of telephone/text reminders for appointments improve attendance (Kim and Oh, 2003).

Key words

- Adherence
- Medication

Authors

Jen Nash is Clinical Psychologist with Central & North West London NHS Trust, and Director of Positive Diabetes.

Page points

1. The choice of medication is of primary importance to ensure adherence in people with diabetes. For example, medications should be selected with the lowest possible daily dose frequency (Morris, 2004).
2. Ensuring that the person with diabetes understands their treatment regimen is crucial and there are three main barriers to comprehension: Health literacy, cognitive decline and language factors.
3. One psychological factor that can influence adherence is "identity" and research has shown that diabetes can challenge a person's identity (Mamykina et al, 2010).

term "non-adherent" in a critical sense, rather than being thoughtful and curious about why the person may be choosing not to adhere. Adherence exists within the context of the person's life, juggling its many and varied roles and responsibilities. It is therefore a dynamic, not static, phenomenon.

Having discussed the definitions and range of concepts to keep in mind when we are discussing adherence, this article will now move on to discuss the factors that impede on adherence.

What are the barriers to adherence?

Biological factors

Of primary importance is the choice of medication. Morris (2004) states:

> *"Probably the simplest and single most important action that healthcare providers can take to improve adherence is to select medications that permit the lowest daily dose frequency possible."*

The focus of this article will not be on medical management specifically. However, the choice of medication and its possible side effects are important factors to consider.

Cognitive and language factors

Ensuring that the person with diabetes understands their treatment regimen is crucial. There are three main barriers to comprehension.

Health literacy

Does the person understand the instructions you are giving them? Asking them to repeat back their medication regimen can help you to assess their level of understanding. Gathering supporting information from family members about the person's cognition level and whether it varies in clinical settings can be useful. Furthermore, contacting colleagues from learning disability services could be warranted if extra support is needed.

Possibility of cognitive decline

Potential cognitive decline in older people can be discussed with older-age psychiatry colleagues and it may be that referral for cognitive assessment is required. If the person with diabetes appears to be forgetful, it is helpful to provide written reminders of medication to aid memory; however, this is only possible if their literacy levels are adequate.

Language factors

An interpreter should be used if the person has trouble understanding English. Sometimes, even if the person's general conversational skills are adequate, some of the nuances of the medical-based language might cause confusion and the person may be embarrassed to say that they do not understand. In cases such as this, it may be helpful to say: "If you haven't understood it's because I'm not explaining it properly".

Psychological factors

There are a number of psychological factors that can affect adherence to medication.

Identity

Our identity is who we perceive ourselves to be. We all have a need for "identity-coherence", which has been defined by Swann and Bosson (2008) as

> *"The maintenance of personas exemplifying enduring conceptions of oneself"*

This identity-coherence is important in the various aspects and roles of our lives and diabetes can pose a challenge to this. Mamykina et al (2010) examined various aspects of how identity could be threatened by diabetes. One participant in their study described how a family tradition was to enjoy bakery-baked bread and this persisted even though these breads were "a bit heavier on the carbs" than many possible alternatives. This is a common example of how family bonding through shared enjoyment of food may conflict with the person's treatment regimen.

The challenge is how we can help people to integrate diabetes into their existing identity. In the example above, could the person share their dilemma with their family members? New and creative ways of fostering bonding and connection with the family could be experimented with, for example, trying out new types of bread together, or playing games with the family around the table.

Relationship between healthcare professional and person with diabetes

The quality of the relationship between the healthcare professional and the person with diabetes is key and as healthcare professionals we must endeavour to foster a warm, empathic approach with the people we look after. Unfortunately, the quality of this relationship is not always within the healthcare professional's control and it has been demonstrated that the person's attachment style plays a significant role.

Attachment theory proposes that individuals internalise early experiences with parental caregivers and form an internal model that determines their view of themselves and others and whether they are worthy of care. These are termed "internal working models" and influence the type of interactions individuals have with others and their interpretations of these interactions (Ciechanowski et al, 2001).

Depending on the quality of the caregiver–infant interaction, one of four attachment styles will be developed: secure, dismissing, preoccupied or fearful (see *Table 1*). A full discussion of attachment styles is beyond the scope of this article. However, it has been demonstrated that people with diabetes with attachments that are dismissive in style have significantly worse glucose control that people with preoccupied or secure attachment (Ciechanowski et al, 2001). A dismissing style develops when the infant receives care that was emotionally unresponsive, leading them to become self-reliant and less comfortable trusting others.

This internal model has been shown to be fairly enduring into adulthood and is a factor that may well be playing a part in an individual's approach to their healthcare team. In individuals with a dismissing style, healthcare professionals can demonstrate consistency to help foster a sense of containment. This can be done in simple ways, such as being on time for appointments.

Social Factors

Social support

Diabetes does not exist in isolation for the person with diabetes – it needs to be negotiated within their social world. It is for this reason that good levels of social support have been demonstrated to improve both glycaemic control and quality of life (Göz et al, 2007; Gao et al, 2013). Having supportive relationships in which the person feels encouraged by those around them can be helpful in both practical ways, for example, encouraging them to attend their health appointments, and to feel that they are not completely isolated (Göz et al, 2007).

Cultural Factors

Many cultures have different paradigms for

Page points

1. The quality of the relationship between the healthcare professional and the person with diabetes is key and healthcare professionals must endeavour to foster a warm, empathic approach.
2. Attachment theory proposes that individuals internalise early experiences with parental caregivers and form an internal model that determines their view of themselves and others and whether they are worthy of care.
3. Social support is very important for the person with diabetes and has been shown to improve both glycaemic control and quality of life (Göz et al, 2007; Gao et al, 2013).

Table 1. Attachment styles (Ciechanowski et al, 2001).

Attachment style	Description
Secure	Securely attached adults tend to have a positive view of themselves, their partners and their relationships. They are comfortable with intimacy and independence and are able to balance the two.
Dismissing	Dismissive adults desire a high level of independence, often appearing to avoid attachment altogether. They view themselves as self-sufficient and not requiring close relationships. They often have a low opinion of their partners and tend to deal with rejection by distancing themselves.
Preoccupied	Preoccupied adults seek high levels of approval, intimacy and responsiveness from partners, becoming overly dependent. They tend to have less positive views about themselves and their partners, be less trusting and may demonstrate high levels of emotional expressiveness and impulsiveness in their relationships.
Fearful	Fearful adults have mixed feelings about close relationships, both desiring yet feeling uncomfortable with emotional closeness. They tend to view themselves as unworthy, mistrust their partners and seek less intimacy, suppressing their feelings.

Page points

1. Many cultures have different paradigms for understanding health issues and their ways of approaching adherence to medical treatments are likely to reflect this.
2. People with diabetes may report a feeling of stigma, partly due to a certain portrayal of diabetes in the media that people with diabetes are not taking responsibility for their health. People with diabetes may also feel different to friends and family as they have to make different dietary choices.
3. There may be discrepancies between a person's actual adherence and .what they are reporting to health professionals. This may be due to a desire to please the healthcare professional or a desire to avid confrontation.

understanding health issues and their ways of approaching adherence to medical treatments are likely to reflect this. Seeking advice from local community/religious leaders and encouraging the person with diabetes to do the same can assist in the integration of medical management.

Stigma

It is common for people to report a sense of stigma at having diabetes. Certain forms of health promotion in the media have possibly reinforced a view that people with diabetes are failing to take proper responsibility for their health (Broom and Whittaker, 2004).

The treatment of diabetes can also compound this sense of stigma. For example, people may feel a sense of difference because they need to make different dietary choices to family and peers (Vermeire et al, 2007) and need to perform self-care tasks in public, for example, injecting insulin. Because of this stigma, diabetes care may be more easily adhered to when at home, or when there is access to a private place. Ten out of twelve participants in one study did not follow their doctor's recommendation to change their treatment to insulin because of stigma (Shui et al, 2002).

As the healthcare professional, it might be helpful to conceptualise this stigma in the same way you might a fear (this fear being the expected aversive reaction of another) – encourage the person to test out the basis for this fear using graded exposure. This involves taking small steps in the desired direction, reinforcing successes and reframing "failures" as an opportunity to learn something about the self.

What are the barriers to people communicating about their adherence?

Difficulty recalling medication details

Difficulty recalling the details of medication taken is very common for people with diabetes (Klausmann et al, 2013). Although diabetes may seem very important to the healthcare professional, it may not take the same significance for the person with diabetes who may have a busy life with its many demands on attention. Use of a diary can help the person with diabetes recall details of their medication. It may be preferable for them to keep notes in their own notebook/diary rather than using the ones provided in clinic. There are also a number of free mobile phone apps that can assist with this, including the Diabetes UK "D Tracker".

Attempting to please the health professional

There is a certain amount of anecdotal evidence that people have a desire to please their health professional, as the "expert" and a potential authority figure. In these cases, it is helpful for the professional to communicate to the person with diabetes that they are an "expert by experience" and that without their expertise being shared, the expertise of the professional is redundant. It is also necessary to give people a new paradigm for how they can "please" us by conveying it is not about getting it 100% right; rather, like any skill, in order to master it we have to closely examine what is not going right so that we can make changes and make it better.

Desire to avoid confrontation

Some people may fear confrontation with their healthcare provider. The best way for the professional to handle this is to avoid a confrontational stance, rather to endeavour for an enquiring, curious stance about medication adherence. It is important that the professional conducts the consultation in a non-judgemental manner and to present themselves in a non-threatening way. For example, speaking with a smile and striving towards a conversational volume (Stenner et al, 2010).

Conversation starters

The following "conversation starters" can help you to address issues of non-adherence with people with diabetes.

Your hypothesis: The person is trying to please you

"I know having diabetes is tough, and many people perceive me as the expert and feel they have to tell me certain things – I understand this and may well do the same if I was in your position. I have a dilemma and I want us to figure it out together. You tell me you are taking your medication and your results do not fit with that – let's work as a team and solve this together."

Your hypothesis: The person is not taking their medication or is skipping doses

"Life is busy enough without remembering to think about diabetes medication. It's really common for people to skip doses for a number of reasons. This is normal and it is part of being human to forget occasionally. Often there are practical changes we can experiment with to lower your chances of forgetting. Do you think you have missed any of your medication this week?"

If they answer in the positive, they are likely to feel exposed and uncertain if you will judge them, so it is important to immediately praise them: "Thank you! It's really helpful to know that you may have missed doses. Is it OK if we think about them in a bit more detail? Tell me what was going on when you forgot? Were you at home or away?" and so on. Examining the circumstances to this level of detail can assist with developing effective strategies to help.

Practical tools to aid memory, such as a dosset box for oral medications, leaving medication where they can see it, using an alarm, or asking a family member to remind them, are all helpful; reassure the individual that none of these strategies have to be forever. Convey that it is a bit like an experiment – you are finding out what helps and what does not. In this way it is not possible to get it wrong or fail; the strategies that don't work can be discarded in favour of the ones that do.

Conclusion

This article has discussed the reasons why adherence may be problematic and provided suggestions for how health professionals can begin to address this topic in the clinic setting. In the time-limited medical appointment, there may not be enough time to fully explore the challenges to adherence. In these circumstances, referral to a clinical psychologist is warranted. Multidisciplinary teams have consistently been shown to improve adherence outcomes and have typically demonstrated beneficial or neutral effects on costs (Nau, 2012).

In terms of future directions, use of technology to support adherence is an important route for exploration. There is evidence that the use of telephone/text-based reminders for appointments improve attendance (Kim and Oh, 2003) and text-based reminders for adherence to diabetes regimens are also being explored.

Diabetes management is a skill and like any life skill, like learning to drive or mastering a sport, at first it is awkward, hard work, and requires an investment of emotional energy. Conveying this message and assisting the individual to identify their barriers to adherence can have a powerfully positive impact on their quality of life. ■

Anderson RM (1985) Is the problem of compliance all in our heads? *Diabetes Education* **11**: 31–34

Broom D, Whittaker A (2004) Controlling diabetes, controlling diabetics: moral language in the management of diabetes type 2. *Soc Sci Med* **58**: 2371–82

Ciechanowski PS, Katon WJ, Russon JE, Walker EA (2001) The patient provider relationship: Attachment theory and adherence to treatment in diabetes. *Am J Psychiatry* **158**: 29–35

Cox DJ, Gonder-Frederick L (1992) Major developments in behavioural diabetes research. *J Consult Clin Psychol* **60**: 628–38

Gao J, Wang J, Zheng P et al (2013). Effects of self-care, self-efficacy, social support on glycemic control in adults with type 2 diabetes. *BMC Fam Pract* **24**: 66

Göz F, Karaoz S, Goz M et al (2007) Effects of the diabetic patients' perceived social support on their quality-of-life. *J Clin Nurs* **16**: 1353–60

Haynes RB, McDonald H, Garg AX, Montague P (2002) Interventions for helping patients to follow prescriptions for medications. *Cochrane Database Syst Rev* (2): CD000011

Kim HS, Oh, J (2003) Adherence to diabetes control recommendations: impact of nurse telephone calls. *J Adv Nurs* **44**: 256–61

Klausmann G, Hramiak I, Qvist M et al (2013) Evaluation of preference for a novel durable insulin pen with memory function among patients with diabetes and health care professionals. *Patient Prefer Adherence* **5**: 285–92

Mamykina L, Miller AD, Mynatt ED, Greenblatt D (2010) Constructing identities through storytelling in diabetes management. Proceedings of the SIGCHI conference on human factors in computing systems. Association of Computing Machinery, New York, USA

Morris AD (2004) Problems of multiple drug therapy in type 2 diabetes. *Int J Clin Pract* **58**: 45–8

Nau D (2012) Recommendations for improving adherence to type 2 diabetes mellitus therapy – focus on optimizing goral and non-insulin therapies. focus on optimizing oral and non-insulin therapies. *Am J Manag Care* **18**: 49–54

Peyrot M, Rubin R, Lauritzen, T et al (2005) Psychosocial problems and barriers to improved diabetes management: Results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabet Med* **22**: 1379–85

Shui ATY, Wong RYM (2002) Fears and worries associated with hypoglycaemia and diabetes complications: perceptions and experience of Hong Kong Chinese clients. *J Adv Nurs* **39**: 155–63

Stenner KL, Courtenay M, Carey N (2010) Consultations between nurse prescribers and patients with diabetes in primary care: A qualitative study of patient views. *Int J Nurs Stud* **48**: 37–46

Swann WB, Bosson J (2008) Identity negotiation: a theory of self and social interaction. In John O, Robins R, Pervin L (eds.) *Handbook of Personality: Theory and Research*. New York, Guildford, 448–71

Vermeire E, Hearnshaw H, Ratsep A et al., (2007). Obstacles to adherence in living with type 2 diabetes: an internal qualitative study using meta-ethnography. *Prim Care Diabetes* **1**: 25–33

"In the time-limited medical appointment, there may not be enough time to fully explore the challenges to adherence. In these circumstances, referral to a clinical psychologist is warranted."