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ACT for non-adherence

Outlining an Acceptance and Commitment Therapy approach to treatment non-adherence

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What already known on this subject?

- Treatment nonadherence is a major global problem, leading to unnecessary distress and morbidity for individuals, and waste at a societal level
- Several psychological models have been applied to understand adherence, but there remains much unexplained variance, and interventions are often minimally effective

What this paper adds?

- We outline how ACT, which sees nonadherence through the lens of psychological flexibility, can be used to enhance treatment decision-making
- We describe applicable techniques and conversations, such as using values as a basis for decision-making or perspective-taking exercises to see new ways for engaging with treatment-limiting self-stories
- The extant evidence base is populated by exploratory studies suggesting positive relationships between psychological flexibility and adherence, and that ACT may provide a feasible approach to nonadherence
Non-adherence to effective treatments - inclusive of medications, physiotherapy, and psychological interventions – is a significant problem in healthcare delivery. The World Health Organisation reported an non-adherence rate of 30-50% in people taking medication for long-term conditions (Sabaté, 2003), which leads to significant adverse clinical, social and financial impacts (Khan & Socha-Dietrich, 2018). This problem is not restricted to medications. For example, uptake of pulmonary rehabilitation groups for COPD (Garrod, Marshall, Barley, & Jones, 2006) and psychological therapy groups for mental health conditions are often sub-optimal (Brebach, Sharpe, Costa, Rhodes, & Butow, 2016; Byrne et al., 2019; Michelson & Sclare, 2009). Despite extensive research on the causes of non-adherence (Kardas, Lewek, & Matyjaszczyk, 2013) and the evaluation of interventions (Conn, Ruppar, Enríquez, & Cooper, 2016), the challenge of non-adherence is still very much present. Early research tended to focus on the communication between health care professionals and patients, and the effects of this on patients’ understanding and recall of treatment information (Ley, 1982). This led to interventions based on information provision and the use of memory aids, which are still widely used. For some these were effective but for many, particularly those who had been non-adherent for some time, such approaches have little effect (Choudhry et al., 2017). Just as health behaviour research has shown that information provision alone is unlikely to change behaviour, and that a focus was needed on motivational and self-regulatory processes, adherence research moved in the same direction. This has included the application of social cognition models focusing on beliefs, goals and motivation to explain and improve adherence (Auyeung et al., 2020; Hagger & Protogerou, 2020). The cumulative evidence base demonstrates that a very wide range of both modifiable (e.g. beliefs; self-efficacy; knowledge; caregiver support) and unmodifiable (age; socio-economic status) factors influence adherence. Readers interested to see the extent of the breadth of factors affecting adherence may want to consult the comprehensive review undertaken by Kardas, Lewek, & Matyjaszczyk, (2013). To help make sense of these many determinants and see areas for intervention, these can be grouped under 3 broad headings, using the Capability,
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Opportunity, Motivation (COM-B) framework (Jackson, Eliasson, Barber, & Weinman, 2014), reflecting the contextual, systemic and intra-personal factors influencing nonadherence. Despite some progress, it is evident that considerable unexplained variance in adherence outcomes remains. Indeed, behaviour change interventions for medication non-adherence often have limited success (Conn et al, 2016), with habit-based techniques showing minimally greater impact on outcomes than those focused on patient beliefs and communication (Conn & Ruppar, 2017). This has led researchers to widen their perspectives, including focusing on other drivers of intentional non-adherence (Weinman et al., 2018) - the ways in which patients make active treatment choices. One such approach to nonadherence is Acceptance and Commitment Therapy (ACT). The model underlying this approach includes multiple emotional, cognitive, attentional, behavioural, and motivational factors that could conceivably contribute to non-adherence and that offer some additional intervention targets and methods. In this paper we describe how non-adherence appears through the lens of ACT, exemplify intervention methods that follow from this perspective, and outline the extant evidence base. We hope the considerations presented here will lead to innovative new approaches to improve the challenging problem of treatment nonadherence.

1. How might clinicians approach non-adherence from an ACT perspective?

What is Acceptance and Commitment Therapy (ACT)?

ACT is a newer approach from within the family of cognitive behavioural therapies. Here a range of treatment methods (mindfulness, exposure, values clarification, goal-setting etc.) are used to engender a quality within one’s behaviour called psychological flexibility, defined as: “...the capacity to persist or to change behaviour in a way that 1) includes conscious and open contact with thoughts and feelings (openness), 2) appreciates what the situation affords (awareness), and 3) serves one’s goals and values (engagement)” (McCracken & Morley, 2014, p. 225). Psychological flexibility is a broad process that can be broken into over-lapping components, such as in the so-called ‘tri-flex’ of
Openness, Awareness, and Engagement indicated in the aforementioned definition (Hayes, Strosahl, & Wilson, 2011).

Commensurate with its position as the treatment target of ACT, psychological flexibility is shown in observational studies to correlate with well-being and effective functioning across a number of contexts – from living with a physical or mental health conditions to performing effectively at work (Biron & van Veldhoven, 2012; Kashdan & Rottenberg, 2010; Machell, Goodman, & Kashdan, 2014). There has been no comprehensive study of the relationship between psychological flexibility and treatment adherence. However, an emerging literature of smaller studies shows relationships between psychological flexibility and treatment adherence. One study showed that uptake of the influenza vaccine was greater among those endorsing higher psychological flexibility (Cheung & Mak, 2016). Another, with a small sample of people with COPD, observed that uptake of pulmonary rehabilitation following an acute exacerbation of symptoms was greater among those showing higher engagement and openness (Fernandes-James, Graham, Batterham, & Harrison, 2019). An online questionnaire study with individuals with HIV demonstrated associations between psychological flexibility and self-reported adherence to anti-retroviral treatment, although these associations were weak in magnitude (Harrison, Scott, Timmins, Graham, & Harrison, 2020).

In randomised controlled trials across applied contexts, ACT shows efficacy for improving functioning and reducing distress (Gloster, Walder, Levin, Twohig, & Karekla, 2020). The strongest evidence is in support of ACT for improving functioning in chronic pain (Hughes, Clark, Colclough, Dale, & McMillan, 2017). In chronic diseases, while higher quality supportive evidence is accumulating (e.g., Hawkes et al., 2013; Johns et al., 2020) the evidence base has largely consisted of lower quality trials (Graham, Gouick, Krahé, & Gillanders, 2016). Although there have been no comprehensive evaluations of ACT specifically targeted at treatment non-adherence, case series of ACT for self-management, including treatment adherence as an outcome, have showed promising results – with post-intervention improvements in glycaemic control in diabetes (Nes et al., 2012) and HIV biomarkers (Moitra, Herbert, & Forman, 2011). A further small feasibility study of ACT for improving
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adherence to intravenous injections for haemophilia, suggested that face-to-face intervention is feasible, but could not comment on efficacy (Hoefnagels et al., 2020).

How might we use ACT to change psychological flexibility to improve nonadherence

The extant evidence suggests that ACT is helpful for improving wellbeing, and there is emerging evidence suggesting that nonadherence could become an appropriate target for ACT. So how is adherence viewed from within an ACT framework and what might ACT interventions involve?

In answering, it is useful first briefly to mention the worldview from which ACT emerges. ACT is informed by a philosophy termed ‘functional contextualism’, including a related behavioural account of language called ‘Relational Frame Theory’ (RFT) (Hayes, Barnes-Holmes, & Wilson, 2012; Hayes, Luoma, Bond, Masuda, & Lillis, 2006). A complete description of either is beyond the scope of this paper. However, given the purposes of this paper, some implications are worth noting because these inform how ACT techniques are used and arguably differentiate ACT from other interventions (Gaudiano, 2011; Hofmann & Asmundson, 2008).

First, ACT is a pragmatic approach to behaviour change that aims to help participants discern and do activities that are in line with their own overarching goals and values, as opposed to reducing distress or doing more or less of a pre-specified behaviour. While successful application of ACT often results in reduced emotional distress and an increase in behaviours that are culturally valued (Gloster et al., 2020), the approach prioritises ‘doing what makes life meaningful’ above ‘feeling better’ or ‘doing what is ‘right’ (i.e. in the eyes of others or society). This pragmatic stance extends into how ACT approaches thoughts. Within the traditional cognitive therapy ethos of ‘collaborative empiricism’, the approach is to seek consistency between thoughts and essential truths about the world, and presume consistency between thoughts, feelings, and action. In ACT the consistency is sought is between behaviour, direct experience, and goals – and this may explicitly include inconsistency with thoughts or between thoughts and feelings and behaviour. Thus ACT is more likely in to involve conversations about effectiveness, ‘does getting caught up with those thoughts..."
Improving treatment adherence via ACT involves having conversations and using techniques aimed at enhancing psychological flexibility. So let us look at nonadherence from the perspective of each of the three aspects of psychological flexibility defined earlier: Engagement, Openness, and Awareness.

**a. Engagement**

Engagement comprises two components: 1) a conscious connection with one’s overarching goals in life (sometimes called ‘values’) and 2) making choices and building wider patterns of behaviour that reflect these values (committed action). We expect adherence to be likely where a person is clear on their values and sees that treatment is itself directly values-based action, or that it helps them engage with other activities that are consistent with these values. Consider a young woman prescribed hormone therapy to prevent cancer recurrence following hospital treatment of breast cancer. Adherence is more likely to occur if she is clear on her values (e.g. kindness, intimacy, creativity) and also notices that the consequences of treatment (symptom control and side-effects) facilitate activity where values are expressed— for example, in her role at work, as a parent, or partner.

*How might Engagement affect adherence?*

Where a person is unaware of their values, without an anchor in an overarching sense of purpose, behaviour may be prone to excessive influence from whatever thoughts, feelings or other experiences happen to be present in a given situation. Thus, where fear and thoughts about cancer recurrence are present, then hormone therapies (preventers of breast cancer recurrence) are taken; where these experiences are not present, then hormone therapies are not taken, and neither one of these options is ideal.

A failure to make a connection between treatment or the consequences of treatment and one’s values could emerge from an unawareness of what treatment can offer beyond control of
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symptoms. For example, not seeing how the improvements in respiratory health following pulmonary rehabilitation groups for COPD facilitate enjoyment of one’s grandchildren. However, given the pragmatic worldview underlying ACT, an individual may also choose to stop taking medication as a values consistent choice. For example, a woman taking hormone therapies following breast cancer may stop taking medication because - having weighed the impact of unmanageable side-effects of hormone therapies (arthralgia, hot flushes, etc.) on quality of life against the likely treatment benefit (% likelihood reduced risk of recurrence) - she sees non-persistence will better facilitate enriching activity (e.g. being present in her relationships).

How might you enhance engagement?

Values provide a framework within which one can discern the effectiveness of choices. Where values are unclear, a therapist might first have conversations that help the individual to see and, as specifically as is useful, to define their values. There are a range of established exercises for values-clarification, such as guided reflections on who you admire or the Values Compass exercise (Harris, 2019; Hayes & Hofmann, 2018)

A practitioner might then invite a participant to view treatment consequences through the lens of values. This could involve reflection on whether treatment consequences are consistent with their values (“Considering how it feels after you go, does attending pulmonary rehabilitation seem more like a step towards or a step away from how you want your life to be?”). If adherence is considered a values-consistent behaviour, then a therapist could help the participant make changes to facilitate adherence. A typical ACT exercise to initiate momentum in broadening behavioural repertoires to include more and more life enriching behaviour is the ‘smallest possible step’ exercise (Harris, 2009). Here, a therapist invites the participant to estimate the smallest possible values consistent new behaviour that they could do over the next week. Applied to adherence (where this is values consistent), participants might decide to set an alarm reminder to take medication, start a conversation with someone in their pulmonary rehabilitation group etc..
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Over time, with the beneficial consequences acting as reinforcers, successive ‘smallest possible steps’ could be added.

It is again important to emphasise that the goal of ACT is to help clients make effective choices, given their own personal goals and values. Therefore, after considering the implications for physical health, particularly from a stance of psychological flexibility, some may judge the most effective choice is non-adherence.

**b. Openness**

Meaningful activities (e.g. first dates, parents’ evenings) do not exclusively include pleasant experiences. These activities also bring experiences with aversive qualities: anxiety, embarrassment, memories of failures, and challenging thoughts. Behaviours such as worry and avoidance might be used as means to control these experiences. This by itself is not necessarily a bad thing. On some occasions, however, our time and energy may be taken up with resisting our own experiences to the detriment of achieving our wider goals. This class of behaviours is sometimes called ‘experiential avoidance’. The opposite of experiential avoidance is ‘openness’, which involves showing willingness to allow experiences to be present, even if they are unwanted, where this facilitates activity that enriches life.

**How might Openness affect adherence?**

We expect non-adherence to be more likely where the behaviours required come with visceral and cognitive experiences (thoughts, feelings, memories, side-effects) that have aversive qualities. We expect this limiting effect to be enhanced further where an individual is also unwilling to have these experiences. For example, consider someone taking anti-retroviral drugs for asymptomatic HIV. The act of taking medication could bring discomfort as opposed to relieving discomfort. It may bring to mind painful thoughts of what HIV might mean for the future, fears of passing the virus to others, etc. If experiential avoidance is a significant factor, then adherence may occur infrequently or not at all. Similarly, where willingness is low, the side-effects that emerge after treatment or the thoughts
or feelings these bring, could become barriers to continuation of treatment. For example, increased bodily pain in the days following pulmonary rehabilitation might make stories of being ‘damaged or broken’ readily available.

In addition to the willingness to have challenging thoughts, the way that the person interacts with thoughts could also affect adherence. For example, thoughts involving ‘making a fool of myself..’ might be common when people consider going to their first group therapy session for low mood. Yet, whether these thoughts can be interacted with as what they are - transitory experiences that one can also choose to observe and not follow - rather than as literal truths may influence whether the person attends the session.

**How might you enhance openness?**

If treatment adherence is considered by the participant to be commensurate with their values, then a clinician could explore which experiences influence adherence. First it may be worth seeing whether side-effects can be reduced, where these are barriers to adherence. Where unwillingness to have experiences that come with medication adherence presents an additional barrier, many methods may help. Almost any new behavior that doesn’t involve the automatic following of urges to resist an unwanted experience can create a break from habitual responses. An individual might instead slow down and observe elements of experience (thoughts and feelings) as they appear, and notice other feelings in the body at the same time. Metaphors could be used to help participants see the possibilities in responding with willingness to challenging experiences. e.g. unwelcome party guest, passengers on the bus (Harris, 2019; Hayes & Hofmann, 2018)

Practitioners could seek to add appetitive functions to the aversive experiences that act as barriers to medication taking. This might involve helping participants to notice the possibility for personal progress implicit in the act of medication taking. Several metaphors offer this perspective. For example, the ‘ticket metaphor’: ‘It’s a bit like a ticket – on the one side you have the show that you want to see (the value and associated feelings included in ‘intimacy’), while on the other you have the cost (embarrassment that accompanies a meeting with the GP to discuss treatment). This
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metaphor nestles pain within values, offering the possibility for pain to be engaged with as something to move towards not always to run from.

Similarly, where thoughts are barriers to treatment (e.g. “I’ll make a fool of myself”), a practitioner could introduce ‘defusion’ methods, which help participants notice the possibility to engage with thoughts less literally. For example, verbal distancing methods such as “I am having the thought that...” or characterising the mind as a radio station etc. (Harris, 2019).

c. Awareness

How might Awareness affect adherence?

Central to PF is the ability effectively to notice, to choose where you attend and from which perspective, so that you can see your choices, what you then do, what influences what you do, and then evaluate the effectiveness of what you have done. Where awareness is a problem, people may find it difficult consistently to make effective choices because they do not adequately track their experiences and the consequences of their actions. Medication adherence may become sub-optimal even with a treatment that offers symptom relief, where someone doesn’t notice these consequences (symptom change). This issue may be greater for medications that do not deliver immediate symptom relief, like preventative medications in asthma, which provide a longer-term prevention of symptoms but offer little short-term relief. Effective awareness involves not only noticing the consequences of actions, but also tracking the situations or experiences that are antecedents to behaviours like (non)adherence. For example, a person showing good awareness may notice that they are less inclined to remember to take their preventative inhaler when they are in great health, and not experiencing difficulties breathing.

Where awareness is problematic, people may also struggle to shift perspectives on their experiences. This could involve getting caught up in judgemental stories about themselves, which could impact on nonadherence. For example, consider, a person with type 2 diabetes, who gets caught-up with stories about ‘being a failure’ and deserving of ill health. From within this stance
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towards themselves they may not see the opportunity to undertake, or to connect with the progress implicit in, undertaking helpful self-management behaviours inclusive of treatment adherence.

How might you enhance Awareness?

To develop awareness, therapists may aim to introduce “tracking” behaviours (Villatte, Villatte, & Hayes, 2015). This involves conversations to enhance noticing of the experiences antecedent to choices to not adhere (“what happens as you consider taking your medication?”), alongside the features of the behaviour and the consequences: “and when you make that choice to not take your medication does anything change?”. Centreing exercises (e.g. ‘notice three things’) can also enable participants to be more in touch with the moment and less stuck in their own thoughts.

Where participants are unhelpfully caught up with stories, a clinician may encourage them to engage with these stories from a different perspective. A shift in person, place or time can help one to see the possibility for new responses that are not apparent from one perspective alone, or are occluded by other experiences. Consider the earlier story about ‘being a failure’, a therapist might help the participant notice other responses by encouraging them to look at the story from the perspective of another person: “Imagine seeing your best friend say that about themselves ‘I am a failure’ … what urges would you have as you heard them say that?” This participant might see the possibility for self-compassionate behaviours that may be more effective: comforting yourself, validating your pain.

From this more self-compassionate stance, effective choices around condition self-management may be more available and the consequences more reinforcing.

Conclusions

ACT sees non-adherence through the lens of psychological flexibility, with intervention techniques arranged to impact on this process. While empirical evaluation is required regarding its utility and effectiveness, it does introduce a broad set of psychological processes, and novel methods that might add to or provide alternatives to existing approaches. The possible uniqueness of ACT methods are emphasised when one considers these against the Behaviour Change Taxonomy (Michie et al., 2013), a widely-applied taxonomy that aims to comprehensively categorise the form
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and/or function of the predominant intervention techniques used in behaviour change interventions. A systematic review of ACT interventions for promoting physical activity (Pears & Sutton, 2021) suggested that many techniques frequently used in ACT could not be readily categorised in this framework, and reasons for this become evident when examining the Behaviour Change Taxonomy. For example, there is no clear place to position acceptance methods for addressing emotional experiences as means to change a behaviour, perspective-taking methods serving functions consistent with the aims of ACT - methods that do not aim directly to change beliefs or emotions, but rather to relate to them more effectively - or values-based methods conceptualised as a quality of action or personally-meaningful ‘direction of travel’.

Nonetheless, it is important to emphasise that adopting ACT methods does not necessarily entail omitting methods one might use in other models (Hayes & Hofmann, 2018). The ACT targets and methods outlined in this paper can be added to change methods used in other models (see Karekla, Karademas, & Gloster, 2019). For example, social cognition models emphasise the role of illness and treatment beliefs informing logical decision making around medications, in addition to this an ACT suggests that relationships with such thoughts and emotions also represent meaningful treatment targets, and that treatment might usefully be placed within a values framework to enhance effective decision making. Further, ACT methods may be added to traditional habit-based approaches. The techniques outlined as supporting the engagement aspects of psychological flexibility can help an individual consciously select behaviours that are consistent with their values, with greater openness and awareness supporting initiation in the presence of aversive competing stimuli. Pragmatic repetition of the behaviour in consistent contexts (Lally & Gardner, 2013) may then transfer the behaviour to a habit elicited automatically in the presence of the necessary cues. Indeed, one recent approach to non-adherence to photoprotection in xeroderma pigmentosum included a focus on values within more traditional strategies to facilitate habit formation (e.g. action planning; Walburn et al., 2020). Alongside planning of when and where a specific photoprotection activity would be enacted, participants placed photos of value related content (e.g., photos of travel destinations
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aligning with value of being adventurous) next to their photoprotective sunscreen as a visual prompt. The COM-B framework is helpful for keeping a clinician aware of the breadth of extra-personal factors that contribute to non-adherence. If taking an ACT approach to help a client with non-adherence, a clinician should be aware that socio-economic or biological (e.g. neuro-cognitive functioning) factors also impact on each person’s behaviour.

We suggest that larger-scale empirical evaluations of ACT interventions for non-adherence are now required. Time and data will tell if these add anything to existing approaches. With ACT principles being some of the most widely applied to psychological problems that occur in chronic disease (Thewes et al., 2014) and mental health conditions, if efficacious, an ACT approach to non-adherence could be readily incorporated into clinical practice.
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Table 1. *Table showing how ACT methods target specific aspects of psychological inflexibility that may contribute to nonadherence*

<table>
<thead>
<tr>
<th>PF Process</th>
<th>Behaviours that indicate this aspect of PF could be enhanced</th>
<th>ACT methods that target this process</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Engagement</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowing and doing what is consistent with one’s over-arching goals</td>
<td>Unawareness of overarching values</td>
<td>Conversations about what is important to the person</td>
</tr>
<tr>
<td></td>
<td>Acting impulsively or inertia</td>
<td>Exercises designed to enhance connection with values</td>
</tr>
<tr>
<td></td>
<td>Not looking at treatment choices/consequences from within the framework of values</td>
<td>Open conversations considering whether treatment/consequences of treatment are a step towards or away from values</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Practice considering clinically relevant behaviours from within the lens of effectiveness</td>
</tr>
<tr>
<td><strong>Openness</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conscious and open contact with thoughts and feelings</td>
<td>Treatment is not adhered to when aversive or competing emotions, thoughts and memories are present</td>
<td>Conversations considering pragmatic ways to manage treatment side-effects</td>
</tr>
<tr>
<td></td>
<td>Behaviour becomes focused on avoiding experiences to the detriment of meaningful activity, perhaps including adherence</td>
<td>Where treatment adherence is considered to be values-consistent, then:</td>
</tr>
<tr>
<td></td>
<td>Thoughts/stories about treatment consequences occlude feedback from experience</td>
<td>Practice reducing the dominance of competing psychological experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(thoughts, feelings, emotions, stories) over behaviour: defusion, willingness exercises and metaphors.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adding appetitive functions to aversive experiences: metaphors/conversations that draw attention to the challenging experiences that are implicit within progress.</td>
</tr>
<tr>
<td><strong>Awareness</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexibly attending to one’s experiences</td>
<td>Not noticing the consequences of treatment</td>
<td>Conversations to help the person notice their behaviours, and what influences these behaviours (tracking)</td>
</tr>
<tr>
<td></td>
<td>Not noticing what influences treatment choices or the eventual effectiveness of choices</td>
<td>Mindfulness to develop the capacity to pay flexible attention to the present moment</td>
</tr>
<tr>
<td></td>
<td>Attention detrimentally focused on past problems/mistakes or future concerns</td>
<td>Perspective-taking exercises to see new possible responses to challenging self-stories (e.g. more compassionate responses)</td>
</tr>
<tr>
<td></td>
<td>Unhelpful entanglement with stories about the self (stories about who you are, aren’t, will never be, will always be) leads to a narrow or unhelpful range of behaviours</td>
<td></td>
</tr>
</tbody>
</table>


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