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**The use of therapeutic untruths by staff supporting people with an intellectual disability who display behaviours that challenge**

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## **Abstract**

**Background:** Therapeutic untruths (TU) are used in dementia services to de-escalate distressing situations. We explored the use of TU by care staff supporting people with an intellectual disability who displayed behaviours that challenged.

**Method:** Data was collected from 126 staff (female = 72.2%; mean age = 41.9 years, SD = 10.7) via an online survey in relation to three areas: responses to three scenarios, reported use of different forms of TU, and ratings of perceived effectiveness of, and level of comfort using, each type.

**Results:** 96% of participants reported using TU themselves and observing their colleagues doing likewise. Models which included perceived effectiveness of, and level of staff comfort with using, different TU were significant, although only perceived effectiveness significantly independently contributed to the model.

**Conclusion:** The use of TU was common, with levels consistent with those found in dementia services. The limitations and implications of the findings are discussed.

**Key words:** intellectual disability; therapeutic untruths; behaviours that challenge; staff attitudes; support staff

## **Introduction**

It is emphasised that staff working with people with an intellectual disability should ‘show dignity, respect, warmth, empathy, and compassion in all interactions’ (Positive Behavioural Support [PBS] Coalition, UK, 2015, p20). This is consistent with the principle that health professionals should be honest in communications with others (General Medical Council, 2015). While lies are a common occurrence in daily life, research also suggests that staff are not always entirely honest with those they support (Cantone et al., 2019). An important distinction has been made in health and support services, however, between ‘therapeutic lies’ or ‘therapeutic untruths’ (TU) and other forms of untruths. TU are used in the best interests of the person being supported, while non-therapeutic untruths, instead are used for the benefit the person providing support (see Cantone et al., 2019). TU can take a variety of forms, including: omission i.e., not providing the person with the full information; going along with the person, rather than challenging their misperception, white lies, outright lies and tricks (Blum, 1994).

Research indicates that untruths, such as ‘fiblets,’ ‘therapeutic lies,’ redirection, and distraction may be used in a range of situations, including as part of strategies to de-escalate aggressive situations (Cantone et al., 2019, see Hallett and Dickens, 2017). Aggression and other forms of behaviour that challenges (CB), are understood as serving a function for the person, often expressing an unmet need (Gore et al., 2013) and recent prevalence of CB in adults with an intellectual disability is estimated as 18.1% (Bowring, Totsika, Hastings, Toogood, & Griffith 2017). Positive and value-based approaches to CB aim to prevent their occurrence by identifying their function and meeting underlying needs (PBS Coalition, UK, 2015) and a ‘PBS plan will also describe an appropriate and ethical range of reactive strategies to guide responses to incidents of behaviour that are not preventable and which aim to minimise escalation and reduce the risk of harm to the person and others’ (PBS Coalition,

UK, 2015, p9). In this context, staff may use reactive strategies to manage CB safely, in the least restrictive way and in a manner that most effectively avoids escalation (Gore et al., 2013). The inclusion of distraction and evasion as examples of reactive strategies that can be used as part of PBS approaches (Allen, James, Evans, Hawkins, & Jenkins 2005), suggest that these forms of TU and others may be being used by staff working in intellectual disability services, but may not have been explicitly acknowledged as such.

Given the ethical complexity of using untruths as part of a person-centred, values-based approach, and the risk that untruths can be used in ways that are not in the best interests of vulnerable people, there is a need for more research and debate about the use of untruths in intellectual disability services. In 2008, Watt outlined some examples of the use of ‘benevolent deceit’ with the aim of promoting debate about the appropriateness of their use with people with an intellectual disability, however there has been limited subsequent discussion or research in this area. This means that the lack of clarity about the acceptability or otherwise of using TU with people with an intellectual disability continues.

The majority of research into the use of TU has occurred within the context of dementia care services. This indicates that TU are commonly used, both in the UK and abroad (Cantone et al., 2019), with up to 97% of professionals reporting using them in the context of dementia care (James, Wood-Mitchell, Waterworth, Mackenzie, & Cunningham, 2006). This use is not, however, without ethical complexity and controversy, with advocates of the use of TU citing the benefits in terms of reducing distress and CB, and increasing wellbeing, particularly when the individual has emotional and/or cognitive limitations that makes it difficult for them to cope with the truth (Cantone et al., 2019; Sokol, 2007). By contrast, opponents argue that it is an immoral and unethical approach which breaches the trust of the person being supported (see Cantone et al., 2019).

Research into the views of people with dementia about the use of untruths also highlights the complexity of the issue. The use of untruths was considered by those with dementia to be acceptable if used in the best interests of the person (Day, James, Meyer, & Lee, 2011). What was perceived as being in their best interests was influenced by factors such as who the person was who was using the untruths, the awareness of the person with dementia that they are being deceived, and the nature of the untruth.

In an attempt to address the complexity of the issue, guidance has been developed for those working in dementia care, about ensuring the use of TU are consistent with, and take account of the needs, level of understanding and timeline of the life of the person being supported (Mackenzie, Smith, & James, 2015). The Mental Health Foundation (2016) has also identified the circumstances under which different forms of untruth might be acceptable.

This guidance is based on the underlying principles of the use of untruths being in the ‘best interests’ of the person, being as close to ‘whole-truth telling’ as possible, taking account of the context of the person being supported, being used within a value-based perspective, being used consistently across all those people involved in the person’s life and being evaluated in terms of effectiveness. The belief that TU can facilitate communication with those being supported (Culley, Barber, Hope, & James, 2013; Seaman & Stone, 2017) has also led to TU being identified as potential communication tools, to be used in conjunction with other therapeutic strategies to negotiate CB (James, 2015). Health professionals, primarily psychologists, have also increasingly endorsed the use of TU and the need to train others in their effective use (James & Caiazza, 2018), suggesting a growing level of acceptance of, and comfort with, using TU in dementia care under certain circumstances.

By contrast, research into the use of untruths with people with an intellectual disability has mainly focused on consideration of the role of omission, in the specific context of disclosure about life-limiting illness to people with an intellectual disability (Tuffrey-Wijne & Rose, 2017; Bernal & Tuffrey-Wijne, 2008). As with the care of those with dementia, non-disclosure of ‘bad news’ to people with an intellectual disability appears to be driven by motives of acting in the person’s best interest, rather than ill-intent (Tuffrey-Wijne et al., 2013).

Other than the perception of what is seen as being in the best interests of the person, little is known about the processes underpinning the decision to use TU. There is some evidence from studies in dementia care that staff discomfort with using TU, the effectiveness of TU in achieving the particular goal, and the extent to which their benefits outweigh the costs may influence their use (e.g. Turner, Eccles, Kready, Simpson, & Elvish, 2017, Elvish et al., 2010). Indeed, research suggests that the views of some staff on the inappropriateness of using untruths do not appear to be influenced by contextual factors (Elvish et al., 2010). This suggests that such staff might experience personal discomfort with using untruths that would influence their use of TU in practice.

To the authors’ knowledge, there has been no research conducted into the general use of TU by support staff working in services for people with an intellectual disability. This is despite a number of parallels between the social care contexts in which both people with dementia and adults with an intellectual disability are supported. This includes the fundamental need for staff to provide values-based, person-centred, high-quality care; to have safe, and effective approaches to CB and to act in the best interests of the person being supported.

The present study, therefore, had the overall aim of exploring the use of TU by social care staff who support adults with an intellectual disability who display CB. The objectives were to identify the types of TU that are used, the extent of their use and to explore whether two factors, perceived effectiveness and degree of comfort in using TU, predict the frequency of their use.

It is hypothesised, based on research in dementia services, that the use of TU will also be relatively common in intellectual disability services. As these services have not undergone the debate about the use of TU, subsequent development of guidelines on their use, and increasing acceptance of their use under certain circumstances, that has occurred in dementia services, staff working in intellectual disability services are likely to experience some discomfort when using TU. It is, therefore, hypothesised that the frequency of use of different types of TU will be predicted by two factors. First, their perceived effectiveness in the safe de-escalation and/or avoidance of the expression of CB. Second, the degree of discomfort caused to staff by their use.

By exploring the type, extent of use, and factors that might influence the use of TU, the study hopes to help inform future debate about the role of TU in intellectual disability services and to identify if there is a need for specific guidance to help staff navigate an area that can be contentious, ethically challenging and potentially open to abuse.

## **Method**

### **Design and ethics**

A quantitative, correlational design was used. Ethical approval for the study was obtained from the first author's university ethics committee.

## **Participants**

Participants were 126 individuals who supported adults with an intellectual disability who displayed CB, in non-NHS settings in the United Kingdom. Fifty-six (44.4%) were support workers, 40 (31.7%) had a role that also involved some managerial responsibilities for other staff, e.g. team leaders, 14 (11.1%) had an NHS background and 16 (12.7%) were classified as other. Thirty-five (27.8%) were males and 91 (72.2%) were female. Ages ranged from 19 to 68 years ( $M = 41.9$ ,  $SD = 10.7$ ). All but four identified themselves as British or white British. The majority ( $n = 73$ , 60.8%) had a vocational qualification; 37 (30.8%) had a degree or post-graduate qualification, the remaining participants who provided information had no qualification, a school level qualification or 'other' qualification. Participants had to be 18 years or older and provide support to a person with an intellectual disability who displayed CB.

## **Materials**

**Therapeutic Untruths:** These were measured using the Best Interest Scale (James et al., 2006). This was developed from previous work into the use and acceptability of TU by staff working in dementia care (Elvish, James & Milne, 2010) building on the categories outlined by Blum (1994). The measure primarily aims to assess frequency of use of different types of TU and comprises three sections: three scenarios to which participants give open-ended responses about how they would respond to the situation depicted; a description and examples of different types of TU; and questions on the frequency with which participants have used, and observed others using, each type of TU, coded on a rating scale.

The measure was adapted for use with staff who supported individuals with an intellectual disability, by making the scenarios more relevant to this service setting.

Participants were asked in an open-ended question to write down how they would respond to three scenarios (see Table 1). The responses were then coded according to type of TU (if

any) indicated in the answer (see Table 2). Two raters independently coded 29% of responses, with 89% agreement between the two. Disagreements over coding were resolved through discussion. The remaining responses were scored by one rater. Any scenario that contained any type of TU was given a score of 1, indicating the presence of a TU. If no TU was present, the scenario was scored as 0. These scores were then summed across the three scenarios, providing a TU scenario score for each participant, with a possible minimum score of 0 and maximum score of 3.

<Insert table 1 about here>

Participants were then provided with a description and examples of types of TUs and non-therapeutic untruths (see Table 2) and asked to rate how frequently they use the six types of untruths on a 5 point scale (never = 0, rarely = 1, occasionally = 2, quite often = 3, often = 4) and how frequently they had witnessed a colleague using each type, using the same scale.

For the purposes of the present study, an additional two questions were included which asked participants to rate how effective they thought using these untruths were in managing behaviours that challenge and how comfortable they were using the untruths. These were scored on a 5 point scale (not at all = 0, slightly = 1, moderately = 2, very = 3, extremely = 4). The questions were then repeated in relation to the use of types of untruths in the past week and in relation to the main person they provide support for, with frequency being given as a number, rather than a rating.

<Insert table 2 about here>

## **Procedure**

Participants were recruited via the authors' existing networks with social care organisations that support people with an intellectual disability and by advertising the study on social media

and on relevant online forums. Potential participants were provided with a brief overview of the study, and a link to the online questionnaire, where they received more detailed information and provided consent by clicking on the 'consent' button. They were asked to provide demographic information and a memorable code (should they wish to later withdraw their data) before completing the questionnaire as outlined above. At the end of the questionnaire they were provided with debrief information. All data collected were anonymous.

## **Analysis**

In order to address the first hypothesis, descriptive statistics were used to present the data relating to the responses to the scenarios, frequency of use of different types of TU, perceived effectiveness and level of comfort using them. In order to address the second hypothesis, a series of multiple linear regressions were used to explore the data relating to the 'previous week.' Perceived effectiveness and level of comfort were used to predict frequency of use for each type of TU. The data for 'tricks' was not analysed due to the extremely low level of reported use.

## **Results**

### **Responses to Scenarios**

Table 3 summarises the number and percentage of participants responding to each scenario with each type of TU and no TU. The mean number of TU used across the three scenarios was 1.5 (SD = .87) with a range of 0-3.

<Insert table 3 about here>

### **Use of TU by self and peers**

Table 4 illustrates the mean scores and standard deviation of frequency of use of each type of TU by self and peers and perceived effectiveness and level of comfort when using each type of TU, in general and over the past week in relation to the main person being supported. A higher mean score indicates more frequent use, greater perceived effectiveness and greater level of comfort using TU respectively. Only 5 (4%) participants reported never using any form of untruth and 5 (4%) reported never having observed their colleagues using any form of untruth. In respect of the past week, 61 (48%) participants reported no use of untruth.

<Insert table 4 about here>

### **Factors predicting the frequency of use of untruths**

A series of multiple linear regressions were run in order to determine the extent to which the frequency of use of each type of TU in the previous week, could be predicted by both the participants' 'perceived effectiveness' and 'level of comfort with TUs' in the previous week,. The predictor variables were 'perceived effectiveness' and 'level of comfort' and the outcome variable was frequency of use of the particular type of TU. The assumptions for multiple linear regression were tested. There was some deviation from normal distribution in the data, in particular illustrated by deviation of data points from the normal distribution line in the P-P plot for the frequency outcome variable for 'outright lies.' The results of the multiple regressions are shown in Table 5.

<Insert table 5 about here>

In all cases, only perceived effectiveness was a significant independent contributor to the model.

## Discussion

The present study aimed to explore the use of untruths by care staff working in intellectual disability services, with a focus on TU, used in the best interest of the people they support. It was hypothesised that the extent of use and type of TU used would be broadly consistent with the results found with staff working in dementia services. The responses to the scenarios, indicated that the most common category of response to scenarios 1 and 3 was to tell the truth, while for scenario 2 the most common response was an omission i.e. failing to tell the person the whole truth. This difference may be because scenario 2 differs somewhat from the others in that it depicts a situation where the full truth may result in more internalised distress for the person being supported, whereas scenarios 1 and 3, suggest that any distress will be externalised, for example, through aggression. This may reflect that staff are more comfortable with dealing with overt behaviour than emotional distress. Between 39 and 59% of responses to the scenarios involved some form of untruth and 22% of responses to scenario 3 involved telling an outright lie.

In terms of general levels of use of TU, the participants reported levels of use for themselves that were between rare and occasional use for most forms of TU, with tricks and outright untruths being less frequent. They reported observing their colleagues using TU more frequently than they reported using them themselves, but with a similar pattern across the different types. Participants reported lower levels of the use of untruths in the previous week, as compared with overall, however over half (52%) had used some form. Overall, 96% of participants reported using some form of TU and the same percentage had observed their colleagues using some form of TU, i.e. in the best interests of the person they supported. These figures are consistent with the results from studies with staff working in dementia services (e.g. Cantone et al., 2019; James et al., 2006), supporting the first hypotheses

The second hypothesis was that the perceived effectiveness of the specific form of TU and the level of comfort experienced by staff when using it would predict the frequency with which types of TU were used. The results illustrated that most forms of TU were rated as slightly to moderately effective, with omission having the highest rating of effectiveness as a response, both overall and in the previous week. A similar pattern was found with level of comfort at using the different types of TU. Outright untruths and tricks were perceived as least effective and caused the most discomfort to the staff member. The results of the regression analyses, found that the overall models significantly predicted frequency of use of the different types of TU, with approximately 25% of the variance being explained by the predictors, with the exception of outright truths, where 17% of the variance was explained. In all cases, only the perceived effectiveness of the TU was a significant independent predictor, with level of comfort making a lesser contribution.

This may reflect a pragmatic response on the part of staff, whereby they will use approaches that they deem to be most effective in a crisis situation, even if they feel uncomfortable doing so. It may also be that, as approaches such as evasion and distraction have been identified as examples of reactive strategies which can be used as part of a PBS approach (Allen et al., 2005), staff feel justified in using TU, which reduces the influence of their personal discomfort on their behaviour.

To the authors' knowledge, this is the first study to systematically explore the use of TU by staff working in intellectual disability services and the results provide an initial step in understanding the factors that influence their use in practice. As with the research in dementia services (Day et al., 2011), the fact that TU are commonly used by staff working in intellectual disability services, raises a number of ethical issues. By definition, TU are used in the best interest of the person being supported, but because they involve deception with vulnerable people who may have limited capacity, their use is also open to abuse and

misinterpretation. There is, therefore, a need for more formal guidance and education about their use, to ensure that TU are used in the most ethical, consistent, and effective way, and with awareness and purpose.

There is also a need to understand how the use of TU fits within a PBS approach, which fundamentally advocates a person-centred, values-based approach and the use of ethical reactive strategies (PBS Coalition, UK, 2015). Research with people with an intellectual disability (McKenzie et al., 2018) and family members (McKenzie et al., 2017) about the factors that are important in good quality care, in particular in relation to PBS, highlighted the importance of being treated with respect and humanity and of open communication. There is, therefore, a need to explore under which (if any) circumstances the use of TU would be viewed by these groups as acceptable as part of a positive, open relationship with staff.

There is much to learn from dementia care services, where debate on the use of TU as part of values-based and person-centred care has been ongoing for a number of years. There has been research with service users about the use of TU (Day et al., 2011), the provision of staff workshops (James & Caiazza, 2018) and the development of recommendations for the use of TU (Mental Health Foundation, 2016). The latter can also offer guidance to staff working in intellectual disability services about the circumstances under which it may be appropriate to use TU. The guidance notes that it is likely to be unhelpful in practice to require staff to never use untruths. Instead it is recommended that staff: ‘always tell the whole truth (or stay as close to the truth as possible) unless it is going to cause unnecessary distress’ (p39).

Our study represents an initial step in understanding the use of TU with people with an intellectual disability, however, it also had a number of limitations. The data used for the

multiple regression analyses, in particular that relating to the use of outright untruths, were not normally distributed. While multiple regression is robust to some minor violation of its assumptions, this limits the generalisability of the models to other samples (Field, 2009). While the sample size was adequate and represented staff in a range of different roles, the majority of participants were female and described themselves as British or white British. Research by Cantone et al. (2019) in Italy, has found levels of use of TU in dementia services to be consistent with those in the UK, however, it is unclear if the present results would be generalisable to intellectual disability services in other countries. Likewise, there may be gender differences in the use of TU.

The nature of the CB displayed by the people being supported was not investigated, nor was the type and extent of support being provided to them by participants. Future research would benefit from exploring both of these factors, as they may influence the use of TU. A further limitation was that the study relied on self-report, which may have resulted in the under-reporting of the use of TU by staff, due to the morally complex nature of the use of TU and social desirability effects. The subjective nature of this self-report and retrospective recall of personal and observed use of TU is also likely to have influenced the results. Further research which is based on the observation of staff practice would help to address this issue. The use of the Best Interests Scale did, however, allow for comparison to be made with the results found in studies in dementia care services, that used the same measure. The study also had a particular focus on social care organisations and further research is needed to explore the use of TU by health professionals.

### **Conclusion**

The study found that the use of TU by staff supporting people with an intellectual disability in social care settings was common, with levels consistent with those found in dementia

services. Models which included perceived effectiveness of, and level of staff comfort with using, different forms of TU were significant, although only perceived effectiveness significantly independently contributed to the model. There is a need for more research in this area and guidance for staff in the use of TU, to help them successfully navigate this complex area.

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**Table 1: Adapted scenarios used as part of the Best Interest Scale.**

<p>John has a mild intellectual disability and becomes upset if his routine changes unexpectedly. His favourite staff member was due to start work five minutes ago, but has called in sick. John is beginning to become agitated.</p>
<p>Amy's mother is terminally ill in hospital and has been unable to visit her as a result. Amy is not aware that her mother is dying and says to you 'I'm sure mum will come to see me today'.</p>
<p>Alex has a favourite t-shirt and becomes aggressive if asked to wear anything else. The original shirt had to be thrown out because it was damaged by the washing machine. His mother has bought a very similar t-shirt to replace it. When you offer this to Alex in the morning, he looks at it for a long time and asks: 'Is this my favourite t-shirt?'</p>

**Table 2: Description and examples of different types of TUs and non-therapeutic untruths as provided to participants**

<b>Untruths</b>	<b>Description of Untruths</b>	<b>Examples</b>
Omission (Withholding information)	Failing to provide the person with the complete information to hand with the intention of reducing distress or getting them to do something.  Not telling whole truth.	<i>“It is a nice day, let’s go for a walk”</i> [In reality the person is being taken for a check-up at another location, but gets stressed when knows in advance].  Person not told that a family member (pet) is ill or in trouble.
Going along	Failing to correct a person’s misperceptions of a situation, which were due to their confusion, misunderstanding, hallucination, or unusual thought processes.	<i>“That will be great!”</i> [Person informs therapist that he is getting discharged this week, but therapist knows this is not going to happen].  <i>“Can you tell those children to go away”</i> , a request from person. Therapist replies <i>“Of course I will.”</i> [the children are hallucination].
White lies	An untruth, which is perceived to be a minor lie because ‘qualifications’ are used. Further, the actual message may be correct at some time in future.	<i>“Go and sit down for a while, I <u>think</u> your favourite programme will be on TV soon.”</i>  <i>“Your husband <u>may</u> be coming today, so let’s get your nice dress on.”</i>  <i>“This tablet is just like a vitamin pill to keep you healthy.”</i> [an antipsychotic]  <i>“I guarantee you’ll get better.”</i>
Outright untruths	Information that is completely untrue, and there is no likelihood the event will come true.	<i>“God never forgives people who take their lives.”</i>  <i>“If you do that again, I’ll call the police.”</i>

Tricks  
(verbal or environmental)

Intentionally using a technique or altering setting to produce a level of confusion that makes the person's behaviour more manageable.

Speaking too fast for the person so that he/she is unable to understand what is being communicated.

Knowingly using overly complex language or terminology to hide a difficult message.

Altering setting or timing of therapy to disguise or manipulate situation.

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**Table 3: the number and percentage of participants responding to each scenario with each type of TU and no TU.**

	<b>No TU</b>	<b>Omission</b>	<b>Going along</b>	<b>White lie</b>	<b>Outright Untruth</b>	<b>Trick</b>
<b>Scenario</b>	Number (percentage)					
<b>1</b>	89 (70.6)	31 (24.6)	0	5 (4)	1 (0.8)	0
<b>2</b>	41 (33.6)	53 (43.4)	8 (6.6)	18 (14.8)	2 (1.6)	0
<b>3</b>	49 (40.2)	39 (32)	0	7 (5.7)	27 (22.1)	0

**Table 4: Mean and standard deviation of frequency of use of each type of TU by self and peers and perceived effectiveness and level of comfort using each type of TU, in general and over the past week in relation to the main person being supported.**

	In General				In relation to the main person supported by the participant over the past week		
	Frequency of use (self) <sup>1</sup>	Frequency of use (peers) <sup>1</sup>	Perceived effectiveness of TU	Reported level of comfort using type of TU	Frequency of use (self) <sup>2</sup>	Perceived effectiveness of TU	Reported level of comfort using type of TU
	Mean (SD)						
<b>Omission</b>	1.69 (.95)	1.85 (.96)	2.2 (1.2)	1.79 (1.1)	1.16 (2.3)	1.48 (1.49)	1.62 (1.4)
<b>Going along</b>	1.58 (.91)	1.75 (.86)	1.7 (1.1)	1.54 (1.1)	.96 (2.5)	1.3 (1.4)	1.33 (1.3)
<b>White lie</b>	1.52 (.90)	1.64 (.90)	1.8 (1.1)	1.70 (1.1)	.63 (1.2)	1.4 (1.4)	1.52 (1.3)
<b>Outright untruth</b>	.60 (.74)	.91 (.78)	.94 (1.1)	1.1 (1.4)	.17 (.66)	.61 (1.1)	.84 (1.4)
<b>Trick</b>	.86 (1.0)	.99 (1.0)	1.2 (1.2)	1.23 (1.3)	.13 (.49)	.70 (1.2)	.86 (1.2)

<sup>1</sup>Mean and SD are calculated based on responses to the 5-point rating scale (0 = never to 4 = often)

<sup>2</sup>Mean and SD are calculated based on reported frequency

**Table 5: Results of the multiple regression analyses for the different types of TU**

	<b>R<sup>2</sup></b>	<b>F</b>	<b>p value</b>	<b>Significance of predictors (p value)</b>		
					<b>Perceived effectiveness</b>	<b>Level of comfort</b>
<b>Omission</b>	.262	11.0	<.001	.001		.725
<b>Going along</b>	.254	9.02	<.001	<.001		.260
<b>White lie</b>	.278	10.58	<.001	.005		.091
<b>Outright untruth</b>	.169	4.79	.013	.009		.686