Taking time to talk: two vignettes to illustrate the tenets of Kitwood's malignant social psychology and application to person centred interactions.

Abstract.

Application of Kitwood's conceptual approach has been widely used in dementia care but has not been previously described in the literature in relation to people with a learning disability. This article describes how Kitwood's concepts around the common communication errors made with people who live with a dementia are also found when working and interacting with people with a learning disability. The authors then go on to describe how adapting malignant interactions to be more person centred can improve relationships, self-value and worth.

Introduction.

Observing others' interactions can inform communities about the worth and value of an individual. If the person is shown respect and trust in conversations with others then they are seen as having a higher status than if they are an adult being spoken to as an unruly child or an adult that has little to offer to the conversation. These socially perceived attributes that are inferred from conversations to surmise the status of an individual are referred to as Personhood (Kitwood, 1997). To deliver person centred care we need to interact with individuals in a way that enables them to have personhood. To do this, we have to value their worth as human beings and engage with them at a mutual level where we can share stories. This enables us to learn about the individuals, their lifestyles, their fears and passions, to learn to understand what will make them sad or happy and why this makes them feel this way so that we may empathise with them.

Kitwood's concept of malignant social psychology.

Kitwood's work is evidenced as extremely influential in elderly care although there is little evidence of his conceptual approach being applied outside of this remit in the literature, despite the approach offering value in its application to different groups of service users where relationships can augment the pathology (Raineri and Cabiati, 2016). Therefore this paper will aim to use Kitwoods theoretical framework to analyse social interactions within learning disability practices.

Kitwood (1997) in his work aimed at improving care and support for people living with a dementia recognises

- the need for comfort in the sense of social belonging;
- attachments and feeling included in the lives of others;
- being involved in their own lives;
- and people being able to have their own identity.

The cognitive degeneration that is seen in dementia alike to the cognitive disabilities seen in people with a learning disability means that health and social care staff, families and friends can either enhance, maintain or reduce these basic psychological and emotional needs and thus undermine or support personhood. Depersonalising or malignant interactions that are not based within person centred approaches thus demoralise personhood while opportunity always exists for us to build personhood through positive interactions and engagement.

This is in line with the philosophy of relation-centred or person centred care where the individual is known through their interpersonal relationship and interactions. This need to acknowledge the psychosocial factors was highlighted by Kitwood and Bredin (1992) who argued that person centred care is good quality interpersonal care which enables personhood, recognition of individuals thoughts, feelings and beliefs, respect and trust. Kogan et al's (2016) literature search on person centred care identified a number of domains including a holistic approach, respect, value, choice, dignity, self-determination or autonomy and purposeful living. These tenets of person centred care are mirrored in the value base of strategies for working with people that have a learning disability as highlighted in the white papers "Valuing People" and "Valuing People Now" (Department of Health, 2001, 2009).

Vignettes to illustrate malignant interactions.

The following amalgamation of case studies aims to illustrate how healthcare staff can undermine or support personhood through their malignant or person centred interactions respectively. The vignette presented here has been amended to remove identifiable information but all events are based on occurrences that the authors have faced over recent years while supporting people with a learning disability.

Vignette 1.

Stanley is a 59 years old man with a mild learning disability who has recently lost his partner with whom he was living with in their own house. Stanley worked as a cleaner before he took on the role of looking after his ill partner. After the loss of his loved one, Stanley was unable to cope independently and was placed in a nursing home. This was an emergency placement which was offered to him due to a paucity of more suitable living environments.

Stanley soon became depressed and reported that he was feeling lonely in his new home. Care and nursing staff attributed Stanley's change in behaviour as part of his learning disability. Hence, when staff would address Stanley, they would refrain from offering him a choice of meaningful activities or include him in meaningful social interactions as they considered he had a low level of understanding and an impaired cognition.

The carers would use words of endearment and motherese when interacting such as "sweetie" or "honey" and utilise collective pronouns such as "Are we ready for our breakfast?" which implied to Stanley and the other residents that he could not complete the activity on his own. Care staff would often give Stanley instructions on how to perform simple tasks, such as teeth brushing despite him previously being independent with these tasks.

Using table one what do you think are the depersonalising interactions from the scenario and think of some alternatives that could be used that would enable person centred interactions?

Vignette 1: What happened next?

When the community nurse visited Stanley, he expressed his concerns regarding the care and support he was receiving. The nurse asked Stanley`s consent to discuss his matter with the Home Manager. Together, they came up with a list of activities which Stanley enjoyed, and which could be

easily facilitated by the care staff. These included setting the tables for meal times, gardening jobs and organising the Tuesday evening Bingo game. Stanley slowly regained his self-esteem, started feeling useful and appreciated and managed to make friends in his new home.

How do you think that the new approach would affect the way that Stanley feels about himself?

Table 1: Applying Kitwood's work to person centred care (adapted from Mitchell and Agnelli, 2015).

Kitwood's (1997) Malignant interactions and examples of depersonalising interactions	To replace with person centred interactions
Treachery Using deception to manipulate behaviour e.g. not telling people the truth in case they become upset.	Being honest with people about their life and ensuring accessibility of information
Disempowerment Not enabling an individual with a learning disability to use the abilities they have e.g. 'it is quicker if I just do it for them' approach.	Encouraging the individual to speak and do for themselves (self-advocacy and independence)
Infantilisation Treating and talking to adults with learning disabilities as though they are a child.	Providing experiences where the person can be creative and spontaneous e.g. with arts and music.. Acknowledging their life history and the stage of life that they are at.
Intimidation Making the person feel that they will not please staff or making them fearful of the consequences of not following your rules / instructions.	Facilitating them to do new things and supporting them to self-advocate.
Labelling Referring to people as a syndrome or inappropriately, for example retard, Down's boy, her with autism.	Recognise the person by their preferred name and recognise that they have their own thoughts, feelings and perceptions.
Stigmatisation Treating the person as an outsider or separating us and them e.g. Service users being told that they have to use different drinking cups to staff, as though they are unhygienic or have a contagious disease.	Including the individual and taking time to find out who they really are, empathising and treating them with respect and dignity.
Outpacing Providing information and number of options available quickly so that the individual cannot process what is said or making information difficult to understand.	Timalation (interactions that focus on the senses rather than cognitions such as aromatherapy) and using the persons preferred augmentary or alternative communication system.
Invalidation Not acknowledging who the person really is and their beliefs e.g. "he can't be a Christian as he doesn't understand what it means".	Accept kindnesses that the person offers. Supporting them to follow their belief systems.
Banishment Excluding people physically, cognitively or emotionally e.g. all staff sitting in the staff office or telling people to go to their room.	Collaboration and cooperation with the person about the task / decisions to gain informed consent.
Objectification Treating people with a disability as though they are an object, for example during washing or dressing.	Getting to know the person and how they feel about situations / events and people to build empathy and respect.
Ignoring Talking with others in front of the person but acting as if the person was not there e.g. talking over the persons head	Provide a safe place that the person can express themselves, actively listening to their responses.
Imposition Implying that the person has to do what they are being instructed to do.	Negotiate, support and cooperate with people so that they can be involved in decision-making
Withholding Not providing attention to people or meeting an apparent need.	Provision of reasonable adjustment including extra time to enable choice and ensuring their rights are met
Accusation Blaming people with learning disabilities for their misunderstanding or inability rather than considering how your communications need to be adapted.	Celebrate the individual's talents and achievements. Break things down into meaningful tasks.
Disruption Needless interference that disturbs an individual who is deep in thought or engaged in an activity.	Being present in the moment and allowing people to engage in their chosen activity in their own way e.g. sitting quietly doing your own art work alongside them to role model and show acceptance of the behaviour.
Mockery Making fun, laughing and joking at the person / people with learning disabilities.	Enable self-expression and to laugh at their jokes and humour; to laugh with and not at the person.
Disparagement Telling or making the person feel that they are not good enough or worthless.	Validate who they are as a person by accepting who they are, their beliefs and values.

Labelling Stanley as having a learning disability and using this to explain his behaviours rather than completing a person centred assessment involving interacting with him about how he feels, what he thinks and finding out his perspective on why he behaves in a certain way resulted in diagnostic overshadowing. Diagnostic overshadowing can be seen when a change in behaviours is attributed to a diagnosis of a learning disability rather than further assessment which looks at the person as a whole to investigate physical and mental health concerns such as depression in Stanley's case. When supporting people with a learning disability it is thus imperative that we remember that although the person has a cognitive impairment it is the social situation, the roles that they have and their interactions with others that "impinges what they actually be and do" (Williams et al, 2015) and thus effects their social and personal identity.

Infantalizing-type communications are where the individual is treated with a stereotypical level of incompetence as evidenced by the communication dialogue, the para-verbal communication (motherese) and non-verbal communication. For Stanley this had a negative effect on his mental well-being and relationship building, this is mirrored in the literature which has shown a negative impact on therapeutic relationships and formulating person centred treatment plans (Duggan et al, 2010).

Vignette 2.

A community carer visits Syed a young man with cerebral palsy. Syad uses a wheelchair so the carer sits at the dining room table with the young man to ensure that they are a similar height, as the carer does not want to stand over Syad when talking with him. They engage in a short conversation about each other's day, this enables the carer to assess how Syad is feeling and address any concerns that he may have. Syad uses his communication book to point to a picture of a sad face and nods when asked if it was something that happened at the centre.

Earlier that day Syad had been at his day provision and had been fascinated by all the different items that were around him as the staff were preparing the room for the next session. When Syad had picked up a pen off the table and then later a disinfectant wipe he had been told "No, don't play with that, give it to me" and "you can't have that" as staff were concerned that he may swallow the pen lid or put the disinfecting wipe in his mouth. The staff member then continued with her task of cleaning and setting up the room leaving Syed without any stimulating objects in reach or offer of an alternative activity while he was waiting. Once this had been completed two staff members took Syad to the bathroom to ensure that he had his personal care completed before he went home, the staff were constantly talking between themselves about how they had been busy all day and what had happened on a TV programme last night.

What are the malignant interactions and what interactions would promote personhood in this scenario? How do you think that these interaction affected Syad?

The lack of understanding about an individuals lived experience increases the chance that the individual with a learning disability is categorised or labelled as well as objectified (Gillman et al, 1997). This objectification is noticeable during personal care of Syad as staff are getting on with the task while talking between themselves, without consideration about how Syad feels or his emotional comfort in the situation. The discourse not only ignores Syad's feelings but also outpaces him as the

conversation about the TV programme does not allow the extra processing time that Syad needs to understand all of the information delivered and thus excludes him from the interaction. By including Syad in the conversation, explaining to him what will happen next and use of timalation through use of scented soaps, body puffs and bubbles the care staff would reduce objectification by considering the person at the centre of their care. The community carer is able to gain information about Syad's lived experience by communicating with him through using his preferred method of communication. This enables the carer to build empathy, as well as recognises and respects Syad's thoughts, feelings and perceptions. Hallrup (2014) explains the importance of actively listening to discourse or descriptions of everyday life as told by people with a learning disability in order to improve care practices, social relationships as well as improve the management and design of services.

The need for person centred actions.

Many people with a learning disability are not afforded the chance to make key life decisions but are confounded by provision available at the time of their needs changing and emerging. Involvement in decision making about key life events and empowering service users to have real choice over everyday decisions is thus one aim of staff supporting people with a learning disability who are following a person centred approach (Donovan et al, 2017). Current literature underlines the importance of providing equal opportunities and choices to individuals with learning disabilities. Dew et al. (2018), emphasize the positive impact of person-centred care planning on the quality of life of people living with a learning disability arguing that this empowers them to express their identity, acknowledge their motivation and picture future goals.

Interactions to discuss options available and enable choice impact not only on an individual's perception of social relationships but also on their self-esteem and feelings of isolation (Bumming, 2004). Feelings of isolation may be expressed as loneliness which reflects an individual's perception that their emotional and social needs are not being met by their social relationships. In people with a learning disability this may increase pre-existing vulnerabilities towards depression and anxiety (Petroutsou et al, 2017) that can manifest as behaviour that challenge service providers or other service users and thus impact building and maintaining social relationships (McVilly et al, 2005). Studies have reported variable prevalence rates of loneliness in people with a learning disability ranging from 45% to 65% (Stancliffe et al, 2010; Guralnick et al, 2006). With strategies needing to consider not only increased quantity of social interactions but also reducing the malignant social interactions by enabling greater choice, self-determination, building social skills and which promote Wolfensberger's (2000) social role valorisation. Thus, strategies which aim to make individuals feel less segregated from their community and more likely to be seen as valued members of the sub-community that surrounds them builds personhood, and reduces the risk of individuals being socially rejected by their community (Gilmore and Cuskelly, 2014).

The tenets of intensive interaction as described by Nind (1996) include people with a learning disability and others enjoying interacting with each other; adjusting interactions so that they become meaningful and engaging for all; assuming intentionality and allowing people with a learning disability to lead interactions and share control over the conversation. Intensive interactions thus attempt to reduce disempowerment, stigmatisation, outpacing, invalidation and disparagement that Kitwood (1997) identified as malignant interactions, which can occur when working with individuals who have a profound and multiple learning disability. Therefore, intensive interactions arguably enables positive social interactions that are closely aligned with person centred care as the staff attempt to understand and enter into the individuals world (Berry et al, 2013).

Fazio et al (2018) argues that person centred care makes life better not only for service users with a learning disability but also those working for them. He goes on to explain that the core recommendations for person centred care are knowing the person; recognising their reality through seeing behaviour as a form of communication from which we can learn about their reality; seeing every activity or experience as a means to engage; being authentic and caring by "doing with" rather than "doing for" people; being supportive and involving wider social networks and finally to evaluate and change interactions and care practices as needed. Furthermore, the NICE Guidelines (2011) stress that healthcare provision should consider the individual's needs and choices, thus making it person-centred. A holistic, individualised approach and involvement in own care planning renders feelings of self-respect and empowerment contributing to enhanced biopsychosocial outcomes for the individual (McCormack and McCance 2017, Morgan and Yoder 2012).

Conclusion.

Application of Kitwood's conceptual approach applied to people with a learning disability has shown the benefit of this conceptual framework to understand how we can improve the lives of individuals with a learning disability through our social interactions. Person centred interactions can impact day to day conversations as well as discourses about life decisions, individuals preferences and aspirations as well as knowing the person and their unique history. The case studies of Stanley and Syad have highlighted how adapting malignant social interactions to be more person centred interactions can improve our therapeutic relationships with people who have a learning disability to enhance their quality of life, mental well-being, self-esteem and self-identity.

> Take home messages for clinical staff.
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> Consider the persons preferred method of communication during social chat, so that the individual may be included in these conversations.
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> Facilitate opportunity to be heard, valued and respected by other people in their social environment.
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> Understand the individual's thoughts, feelings, preferences and aspirations through your interactions with them.
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> The more time that we take to really know someone, the more that we are able to respect, value and empathise with them.
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> Include individuals in decision making and promote self-advocacy by actively listening to the person and encouraging others to do the same.

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