Person-centredness, ethics and stories of risk

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Abstract

Story telling can be a powerful way to reflect on the ethical issues that emerge in clinical practice. This paper uses two stories by speech language pathologists to explore how notions of person centred practice may influence speech language pathology practice. Then these stories are examined in relation to definitions of person centred practice and speech pathology code of ethics to discuss the ethical issues, challenges and risks that these stories raise. Moving towards more person centred ways of practicing will require speech language pathologists to be open to the real lives of their clients with communication and swallowing disabilities. It may also require speech language pathologists to be open to their own vulnerabilities as well.

Key words: person centred practice, ethical practice, narrative, risk

The concept of person-centred care can be difficult to translate into clinical practice (Gillespie, Florin, & Gillam, 2004). This paper uses two narratives to explore how person centred care may be applied to speech language pathology practice and to discuss the ethical issues that emerge. We briefly introduce concepts of person-centredness, and professional and clinical ethics to consider notions of risk raised in these narratives. Story telling is a powerful way for speech-language pathologists to reflect on ethical issues surrounding person-centred practices.
Narrative 1: I took her home one day from the aphasia group. And, I don’t know how it came about. We agreed to go to the Elephant and Castle\(^1\) for a drink. And she wanted to pay but I didn’t feel I could let her pay and I could just sort of sneak it in… (gasps). She was so angry with me for paying for this drink and she gave me the money back! She practically threw it at me, I think (laughs), and she was very cross… but we had a lovely drink…

She wanted to go to the stroke dinner. So I said “Sure, I’ll take you”. That was when she was living at that hostel down at Kingston. So I picked her up, and fortunately a friend came along, and took her to this dinner and she spent half the evening out in the next room at the bar buying herself red wine and chatting up the barman (laughs). By the time we got to take her home, she was as drunk as a monkey. So we took her down the Avenue, went to a pizza place to buy a coffee. While I was waiting for the coffee, she took ages and ages and ages and I went into the toilet and she was sobbing at the top of her voice. She’d locked herself into the cubicle and so I had to get her out! And she came out, she was still drunk, sitting at the table sobbing and crying and telling me she was sorry. And then I think I had trouble getting her out of there. She probably refused to go but she eventually left… and I was still her therapist! And at midnight, there we are ringing on the door of this hostel and I am depositing this drunk woman. I just left. (laughs) That was very funny… I knew Lillian was very much on her own and she really wanted to go so I was quite happy to do that for her. But I think on those other occasions when I took her out, I don’t think I was seeing her (for therapy) at that time. And, again you know, she was on her own and I knew that she’d really appreciate it and because I think that stroke

\(^1\) Names of people and places have been changed
dinner really set the precedent. She enjoyed it so I said “well, you know, we’ll do it again occasionally. Stay in touch”.

This narrative was told by a speech pathologist who had been for a drink with a client and later to a dinner. The client, Lillian, was a single woman in her 60’s who had led a bohemian lifestyle, a lady for whom socialising had been very important. Her stroke had left her with a fluent, jargon aphasia. She had no family and her social options had shrunk completely. The speech pathologist, Tania, knew her through an aphasia group that was focussed on conversation and extending social opportunity. To take Lillian out was possibly seen by the clinician as an extension of this. But the story raises interesting questions that have wider implications. What exactly was Tania’s role on the evenings they went out together? Was she there as a friend or a therapist? Was she bound by a ‘duty of care’, for example, not to allow Lillian to drink so much (possibly medically unwise considering her vascular history) or stay out so late? What if Lillian had decided to go home with the barman? Or had hurt herself while locked in the toilet cubicle? What are the boundaries of the clinician-client relationship?

Agreeing to go out socially with Lillian created a certain unease for Tania. On the one hand, she knew that Lillian was “very much on her own” and had few opportunities to go out. She also knew that Lillian was quite unhappy with her changed situation, really wanted to go out and was very appreciative of the social opportunities that Tania made possible. On the other hand, Tania also expressed some uncertainty about the nature of their relationship when they did go out. A good example of this was their disagreement
about who should pay for the drink. Lillian wanted to pay for Tania’s drink, as a friend might, and became angry when Tania protested. However, Tania felt she couldn’t let her pay and tried, unsuccessfully, to “sneak” the money in. A second example was Tania’s attempts to sober her up with a coffee before taking her home to the hostel, perhaps embarrassed and concerned at “depositing this drunk woman” on the doorstep. Tania felt some degree of responsibility, commenting “I was still her therapist”.

This story shows how extending a client’s social opportunities into real life social situations with a clinician challenges traditional professional boundaries and introduces elements of risk. It also challenges the notion of what is therapy. When she was out, Lillian did not conform to the sick role (see Waterworth & Luker, 1990). She was no longer simply a client. Similarly, Tania, possibly one of the few people who could cope with Lillian’s significant communication difficulties, was no longer simply her therapist. And yet, these social opportunities were perhaps still therapy of a different kind, and occasions that may have held enormous value for Lillian in reclaiming her identity post-stroke.

Our second story was reported by a clinician after attending a person-centred planning workshop:

*Narrative 2: An agency for children with disabilities and their families was becoming more family centred in their philosophy and practice. Part of this transition involved the shift to providing families with individualised funding packages. This meant that instead*
of the agency using the money allocated from the government to provide therapy services for the child, the family was allowed to decide how the money would be spent. One family with a school-aged son with a disability decided to buy a spa with their money. Boys from his class started coming over to his house after school to play in the spa. The family was very happy. For the first time ever, their son was having friends over to play.

This story describes how expanding a client’s therapeutic opportunities, by handing over power to the family about spending resources also entails risk. Once again, the clients (in this case, the child’s parents, as well as the child himself) did not do what the agency was expecting, that is, spend the funds on therapy services, including speech pathology. One assumes that the professional recommendation was that such therapy was required. Moreover, the therapists in the agency might have felt their jobs were vulnerable if such decisions happened too often. While we don’t know from this account whether any education, information, support or negotiation occurred between the service provider and the family, we do know that the family’s decision made them happy and gave their son immediate social opportunities with his peers that no amount of individual therapy could provide. But reflecting on this story also reveals ethical issues about the best interests of the child and secondary benefits to the parents (considering owning the spa would increase the value of their property, and that they are just as likely to be using it themselves). How would this story be different if the money were spent on a luxury holiday for the family or to help pay off the mortgage? One could argue that the decreased stress would eventually benefit the child, but where does the argument stop?
What are the boundaries of person-centred or family centred practice and what are the professional responsibilities?

These stories reflect an emerging trend in speech pathology practice and healthcare generally towards the development of policies and services that are ‘person-centred’. However these stories also show that developing more ‘person-centred’ ways of practising can involve uncertainty and risk. Are uncertainty and risk integral to practising in a person-centred way? What are the risks and how can they best be managed? This paper considers the importance of listening to and reflecting on stories such as these and discusses their implications in relation to literature on person-centred practice and ethics.

*What is a person-centred approach?*

A person-centred approach can be traced back to the introduction of client-centred therapy by Rogers in the context of non-directive psychotherapy (Rogers, 1946). In health care, person-centredness was first described as the need for the clinician to understand the client as a unique human being (Balint, 1969), as a way of practising that was informed by the concepts and insights of the behavioural sciences (Tait, 1974) and as a method directly opposed to disease-centredness or clinician-centredness (Levenstein, McCracken, McWhinney, Stewart, & Brown, 1986).

The concept of person-centredness, sometimes referred to as ‘client-centredness’, ‘family-centredness’ when considering the client as well as the client’s social environment or ‘patient-centredness’ as it is often described in medical literature,
continues to develop as it is applied to different healthcare contexts such as general
practice (Little, Everitt, Williamson, Warner, Moore, Gould et al., 2001) and
rehabilitation (Law, Baptiste, & Mills, 1995) and to people with different healthcare
needs including people with acute care needs (Gerteis, Edgman-Levitan, Daley, &
Delbanco, 1993) and people with chronic health conditions (Michie, Miles, & Weinman,
2003). The ongoing development of the concept of person-centred practice has also given
rise to the related concept of ‘relationship centred’ practice (Tresolini & Pewter-Fetzer
Task Force, 1994). Although a universal definition of person-centredness continues to be
debated (Bensing, 2000; Stewart, 2001), it has been described as having three underlying
values: the acknowledgement of the clients’ needs, perspectives, and experiences; the
offer of opportunities for the clients to participate; and the understanding and the
enhancement of the client-clinician relationship (McWhinney, 1995). In addition a review
of the literature of person-centred medicine proposed it differed from the medical model
of care in terms of five key dimensions. These are a biopsychosocial perspective, the
client as a person, shared power and responsibility, a therapeutic alliance, and
recognising the clinician as a person (Mead & Bower, 2000). A biopsychosocial
perspective acknowledges that health cannot be fully described without a combined
biological, psychological, and social perspective and that these components are
interactive. The client as person refers to the importance of understanding the client’s
unique experience of illness. Sharing power and responsibility promotes an egalitarian
client-clinician relationship, respecting the client’s expertise and autonomy. The
therapeutic alliance refers to the quality of the clinician-client relationship and its
fundamental role in the clinical encounter. Finally, the clinician as person recognises the humanity of the clinician and its inherent impact on the client-clinician relationship.

**Ethics**

Speech language pathologists are also guided by the Code of Ethics of their professional body. For example, a code of ethics exists for speech language pathologists in Australia (Speech Pathology Australia, 2000), Canada (Canadian Association of Speech Language Pathologists and Audiologists, 2005), the United States of America (American Speech-Language-Hearing Association, 2003) and the United Kingdom (Health Professionals Council, 2004). These codes outline the ethical principles on which speech language pathologists base their practice, and include principles such as beneficence/non-maleficence, truth-telling, justice, autonomy and professional integrity. Codes of ethics also specify values (such as respecting the unique dignity of each individual) and duties to clients and the community (such as practising to the highest standards of professional competence). Codes such as these focus on the conduct of members of a profession and the character virtues of those professionals. They have to be brief and broad, providing an initial starting point for more in-depth consideration of individual cases.

Catt (2000) points out that codes of ethics run the risk of being a minimum standard unless the following is applied: abstract rules need to be integrated into daily practice, they need to be client-centred, and professionals need to use the language of ethics in everyday discourse. Catt (2000) sees that clinical decisions are therefore often ethical decisions: “Like clinical problems, ethical problems involve investigative work,
reflection, analysis and good judgement” (p.143). Ethical deliberation should permeate clinical decision-making because personal interests and values of clients are at stake. Such ethical deliberation involves clarification of the problem (the facts, uncertainties, opinions, beliefs, values etc), consideration of guiding principles, weighing of harms and benefits and analysing external factors and influences. It also requires looking at problems from different perspectives as people have different values. Ethics requires dialogue but also reflection and reasoning.

As pointed out above, professional codes of ethics are concerned, not only with conduct, but also with character (Pellegrino & Thomasma, 1993). Professional virtues (virtue being a disposition to act well as a matter of discipline, reflection and habit) include loyalty and stewardship (we are stewards of our professional knowledge and therefore must preserve, validate, teach and make it accessible for those who need it to help others), compassion, truth-telling and trust which flows from the previous two. Trust in the client-clinician relationship is a moral imperative because clients are inescapably vulnerable (Catt, 2000). Therefore our clinical relationship is a fiduciary relationship: clients must trust clinicians and clinicians must be trustworthy.

Narratives, person-centred practice and ethics

In the first story, it is unclear whether Tania went out for a drink with Lillian as her therapist in order to expand her client’s social opportunities or if she viewed their outings as beyond any professional remit. Tania’s story suggests that she was not entirely sure
herself. However, her story does provide the opportunity to think about this scenario and consider whether it is an example of person-centred practice and its ethical implications.

We contend that Tania was certainly person-centred, but question whether it was person-centred practice. Even if Tania’s actions were considered to be therapeutic, were they ethical? These questions can be explored further by considering this narrative in terms of the five dimensions of person-centredness identified by Mead and Bower (2000) (see Table 1).

Insert Table 1 here

By examining this narrative in terms of the five dimensions of person centredness described by Mead and Bower (Mead & Bower, 2000) it is apparent that in order for this intervention to be person centred practice Tania would need to consider the therapeutic aspect of her role more fully. For example, she would need to be clear about the goals of the intervention. Is Lillian’s need for ongoing social outings a therapeutic goal? If so, Tania would need to consider if one or two outings with Lillian would lead to ongoing social participation or whether there were more sustainable ways to address this issue with Lillian, such as by finding ways to broaden her social network and address her transport disadvantage through the various groups and organisations that are equipped to help. Hence Tania may have enlisted the assistance of other professional to help Lillian with these issues and provided the communication support and education to achieve this. Thus the speech-language pathologist’s role would be to enable social participation, not to be the social participant. We do however acknowledge that in order to do this, we need
to step into the real lives of our clients with the compassion that is at the heart of professional practice.

The ethical implications of this narrative are closely related to those raised in the literature on person-centredness. For example, Tania is not directive or paternalistic. She certainly sees beyond the impairment to the broad social consequences of Lillian’s aphasia. She is keen to support Lillian’s autonomous decision-making as well as her best interests in increasing her social opportunity. In this story, supporting these two principles does not cause a clash. However, had Lillian decided to go home with the barman, or had she been instructed previously to avoid alcohol by her medical practitioner, Tania would have had to weigh up respecting Lillian’s autonomy with her best interests. Equally, the relationship is central to an ethical discussion of this case.

Tania demonstrates real compassion for Lillian. Martinez (see Kushner & Thomasma, 2001) describes compassion as different to empathy or sympathy because it involves some act or intervention aimed at reducing or alleviating the suffering. Tania does not simply feel sorry for Lillian with regard to her social isolation. She agrees to take her out. Her actions can be seen as supererogatory, going beyond the call of duty. In order to be supererogatory, such acts must be voluntary, exceeding expectations, for the benefit of another and intrinsically good.

One could argue that, by going beyond the call of duty, Tania has stepped outside her therapeutic role. However, Meier and Purtilo (1994) point out that rehabilitation teams
continue to have some responsibilities after discharge from rehabilitation units and should be involved in assisting community reintegration:

“All too often, rehabilitation professionals are not prepared to assist patients in the not-necessarily-friendly environment outside the rehabilitation unit… professionals must expand their involvement into the community context as well.” (p.366)

They go on to suggest that remaining detached is limiting and that friendship is a useful model for the ongoing relationship serving as a way to balance the problems of a more paternalistic model:

“Friends understand each other in the community and the workplace and know what causes pleasure or sadness and what gives meaning to life. To understand more of the essence of a patient’s life is the responsibility of rehabilitation providers. Rehabilitation professionals must explore new ways to develop inclusive systems that emphasize friendship. This will empower patient-friends to survive, adapt and succeed as newly transformed persons.” (p. 366)

These viewpoints are interesting because they challenge the very models in which speech pathologists often work. Involving notions of friendship may take the argument beyond a relationship that might be considered person-centred practice. There may be valid concerns about over-reliance, an inability to draw boundaries on the relationship, and
eventual breakdown in trust. However, MacCleod and McPherson (2007) cogently argue for a central role of compassion in person-centred care.

The second story describes a service for children with disabilities and their families that explicitly embraced a family centred approach. This service’s policies and practices clearly exemplified the values identified by McWhinney (1995) of person-centredness, in that the service acknowledged the client and his family’s needs, perspectives, and experiences; had created policies and practices that ensured clients participated fully in decision making, and had a very trusting client – service relationship. Table 1 considers this story in terms of the dimensions of person-centred practice identified by Mead and Bower (2000).

According to the five dimensions of patient centred care (Mead & Bower, 2000) the key issues that require clarification in this narrative are around the extent to which there was shared power and responsibility in the decision making and the extent to which the clinicians are considered as people. For example, if there was shared power and responsibility in decision making then the service and the family would have worked together to consider the range of interventions that were possible, given the resources available to increase social opportunities for the child. The service may also have had the responsibility to evaluate whether the chosen intervention (purchasing a spa) achieved this goal. This narrative also indicates that there is the need to consider the clinicians as people in the therapeutic relationship. In order for services to work in person centred ways, clinicians need to be valued partners in the development of goals, intervention
strategies and in the evaluation of intervention strategies so that the family concerned and
families in the future can be as informed as possible.

Can ethical principles guide us with this story further? Again this second narrative is
concerned with the client’s autonomy. In this circumstance it is the autonomy of the
family that is being considered here. Like the previous story this narrative also
demonstrates the principle of autonomy as being central to person-centred practice. The
principle of beneficence/non-maleficence is also critical in this story. In order for person-
centred practice to be successful the service must trust that the family has the best
interests of the child as their central concern and are making decisions that they truly
believe will benefit the child. Truth telling may also be an integral principle for this
service to function as a person-centred practice as the family would rely on the service to
tell them what they know and what they don’t know about facilitating social interaction
in school aged children so that both the family and service can take the risk and try
something new.

Conclusion

Telling our stories provides a useful way to bring real clinical dilemmas to the fore so
that we can reflect on them and share them with each other. We have professional ethical
guidelines but they only come to life when applied sensitively to real cases. Real stories
also highlight the challenges and risks we experience as we move towards more person-
centred ways of practising. These stories suggest that becoming more person-centred in our practice does involve uncertainty and risk. There is the professional uncertainty and risk that is part of genuinely asking our clients what they need and how they can achieve their goals. This may mean being directly involved on some occasions, a consultant on others and a reviewer and translator of available research evidence on others. We will need to be willing to assess and manage our clients’ communication disabilities in new and often challenging contexts. We will also need to relinquish some of the power and security that comes with defining communication and swallowing disabilities solely from a clinician’s perspective. This professional uncertainty may even mean we question very fundamental ways about how and what we practice.

Working in more person-centred ways also brings personal uncertainty and risk. Really listening to our clients, really understanding what it is like for people to live with a communication disability and being willing to step into their lives with genuine compassion requires that we open our hearts as well as our minds. But it exposes us to our own vulnerabilities and needs as well.

Moving towards more person-centred ways of practising will challenge us both professionally and personally. Sharing our stories about person-centred practice provides a way for us to reflect on our practice, and perhaps also to reflect on ourselves. As Geller (2006) wrote, when describing story telling amongst physicians:
“Self-reflection and ‘meaningful’ story-telling on the part of physicians are not only tools for unmasking vulnerabilities and self-awareness. They are also means of cultivating wholeness… of developing a greater connection to one’s own heart, passion, values and humanity” (p.84).

Learning Outcomes. At the end of this paper clinicians will understand how the concept of person centred practice raises new challenges for speech language pathology, and that telling our stories and reflecting on these stories can help translate person centred practice into clinical practice.

Continuing Education Questions

1. A person centred approach has been described as having the underlying values of:
   a) the acknowledgement of the clients’ needs, perspectives, and experiences,
   b) the offer of opportunities for the clients to participate,
   c) the understanding and the enhancement of the client-clinician relationship,
   d) all of the above.

2. Mead and Bower (2000) differentiate person-centred medicine from the medical model of care in terms how many key dimensions?

3. One of Mead and Bower’s (2000) key dimensions relates to the sharing of power and responsibility. This is intended to:
   a) reduce the clinician’s responsibility for clinical decisions made,
b) promote an egalitarian client-clinician relationship,

c) respect the client’s expertise and autonomy,

d) b) and c) above,

e) all of the above.

4. Professional codes of ethics:

   a) describe the conduct of members of a profession,

   b) describe the character virtues of those in the profession,

   c) can be used to as an initial starting point for more in-depth consideration of individual cases,

   d) are brief and broad in scope,

   e) all of the above.

5. Clinical practice in the second narrative appeared to be based in part on the following ethical principle/s:

   a) paternalism,

   b) respecting the client’s autonomy,

   c) reflection,

   d) dedication,

   e) all of the above.

Answers
Table 1: Application of the five dimensions of patient centredness to speech-language pathology narratives

<table>
<thead>
<tr>
<th>Five dimensions of patient-centredness (Mead and Bower (2000))</th>
<th>The application of each dimension to Scenario 1.</th>
<th>The application of each dimension to Scenario 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>A biopsychosocial perspective</td>
<td>Tania was working with Lillian in an aphasia group. She not only understood Lillian’s aphasia in terms of her linguistic deficits but also appreciated the psychological and social implications.</td>
<td>The service acknowledged the psychological and social implications of the child’s disability on the child and his family.</td>
</tr>
<tr>
<td>The client as a person</td>
<td>Tania understood that Lillian had no family, was no longer living in her own home and had been a</td>
<td>It is likely that the service really listened to this family and gained an</td>
</tr>
</tbody>
</table>
fiercely independent and socially vibrant woman. Tania recognised that for Lillian living with severe aphasia was nothing short of devastating.

understanding of what it is like to have a child that never gets asked over to another child’s place to play and never has another child wanting to come over to play.

| Shared power and responsibility | It is unclear in the narrative who initially suggested that they go out for a drink. However if Lillian did ask Tania to go for a drink, it could be argued that she and Tania had successfully negotiated a more equal relationship between them. However, an equal sharing of power and responsibility demands that the clinician’s expertise and autonomy also need to be considered. Tania, as Lillian’s therapist is required to consider Lillian’s proposal in the context of her own expertise as a speech language pathologist and |
| The family and the service providers may have shared their different knowledge and expertise on ways children with disabilities can be supported to make friends. |
reflect on whether Lillian’s proposal is a viable way of achieving her goals and what the implications of this proposal might be.

| A therapeutic alliance | A person-centred approach suggests that the personal relationship between the client and the clinician has the potential to be therapeutic in itself. If Tania declined the offer of going out would she have jeopardised the positive relationship between them? However, by accepting the offer of a drink, has Tania moved the relationship beyond a therapeutic one to a relationship that more closely resembles friendship? Has it limited her capacity as Lillian’s therapist? | A high level of communication would have been necessary to create the very strong therapeutic alliance required to allay any fears that service providers may have had about how the money was being spent. |

| Recognising the clinician as a person | Tania had got to know Lillian well. She clearly liked her, enjoyed her outings (at least, most | Individual clinicians would need to feel like valued partners in the process. |
of the time) and was keen to help. They would also need to be aware of their own values and how these might conflict with the values of the family.

She knew she was making Lillian happy and she also felt appreciated.

References


