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Title

Enhancing storytelling and quality of life for people with severe cognitive impairments using ‘collaborative stretching’: a simple evidence-based strategy

Manuscript

The adventures of the Blue Bouncing Ball (a ‘stretching’ vignette)

I was a teacher of six teenage students with severe intellectual disabilities and other impairments who attended a support class at their local high school. They attended in wheelchairs and required full assistance to engage in most activities. Each had their own personality, talents and strengths but struggled to communicate verbally so they had limited voluntary contact with their age peers. We did though integrate them in most whole school and some age peer activities.

During recess and lunchtimes a group of mainstream students enjoyed a vigorous game of basketball adjacent to our verandah. Their ball would often bounce onto the verandah to be gathered up by a scurrying, apologetic student bent on getting ‘out of our students’ way’ to restart their game. We took advantage of this frequent excitement to refer to our visitor as ‘the blue bouncing ball’.

One afternoon I placed the borrowed basketball at the front of the class. With the attention of the students secured I told a rollicking tale of the fictional adventures of the blue bouncing ball. Laughter, smiles and other positive cues greeted the story. Considerable assisted dialogue and discussion followed. My teaching aid suggested we use this story as the basis for an extended learning experience for our students. Following lengthy discussions, we implemented a diversity of initiatives, building on that first very successful storytelling event to extend and improve our teaching/learning program…
During lunchtimes we prompted our students to watch the (blue bouncing) ball (BBB) and to predict who it might bounce into next; this became a popular ‘adventure’ game!

After lunches we shared a new BBB adventure story which led onto a language and communication lesson. These stories developed out of the students’ widening experiences and imaginations.

We purchased our own BBB (in actuality this was a large bean bag ball) and strategically shared its ‘supervision’ amongst our class members, including taking the BBB home as a prop for focused / scripted communicative engagements with family members.

As each day commenced we discussed our schedule of lessons with frequent humorous references to the participation of the BBB. A wicked sense of humor emerged from amongst the students.

We invited the ‘basketball kids’ into our morning lessons for ‘meet and greet’ sessions. Initially ‘conversations’ were mostly around basketball (with the directed support of staff.) Friendships developed and other common interests were discovered. (Other mainstream students also commenced tentative visits.) Spontaneous stories from both groups of students about the further adventures of the BBB often featured in these visits.

We collected digital photos and film clips of familiar people and places and later novel places, activities and events. These became incorporated into teaching/learning activities through our daily BBB adventure stories.

Through this innovative program storytelling was used as a powerful facilitator of student engagement in learning for students with severe intellectual disabilities who gather relatively
limited lived experiences. By ‘stretching’ our storytelling we ‘value-added’ to our students’
learning and lived experiences, and created so many more opportunities to improve their
quality of life.

In this paper we discuss the evidence base for the concept of ‘stretching’ as it applies to
individuals with severe cognitive impairment (SCI) and provide an outline of the basic steps
required to utilize the stretching strategy in a storytelling event.

Introduction

People with (SCI) include those diagnosed with advanced dementia, severe
intellectual disability or severe acquired brain injury.¹ SCI deleteriously impact thinking,
understanding, memory and behaviour (World Health Organization). For older people with
advanced dementia these impairments deteriorate progressively and are fatal. Individuals with
SCI are impacted throughout the lifespan but regardless of intellectual functioning, all people
are able to learn (Foreman, 9). People with SCI require fulltime care and support for most of
their daily living activities wherever they reside (Stolk; Maslow and Heck). They have the
same rights to happiness, subjective well-being and a (best) quality of life as all others
(Fyson) but their quality of life is essentially dependent upon others around them (Hoe et al.);
their ‘collaborating others’, family, carers and other support persons (Cummins; Courtenay,
Jokinen and Strydom).

Storytelling is one way to enhance the happiness, subjective well-being and quality of
life of all people (Bazan-Salazar; Burns; Boyd) but getting the most out of storytelling for
audiences of people with SCI poses a significant challenge to both storytellers and others
responsible for providing daily ongoing care and support (Grove and Harwood "How
Storytelling Contributes to Quality of Life for People with Learning Difficulties"). This

¹ This paper focuses on people with advanced dementia and severe intellectual disabilities as it is less likely that
storytellers would conduct performances for groups of people with acquired brain injury, because people with
ABI tend to reside in the family home, rather than in group situations.
challenge arises primarily because cognitive impairments generally ‘get in the way’ of efficacious communication, understanding of meaning and memory (Grove et al. “Sharing stories of everyday life with adults and children who have severe/profound intellectual disabilities”). These impairments usually diminish the intensity and duration of the benefits of positive storytelling experiences (Simmons; Boyd). Storytelling has not been used widely with audiences of people with SCI although some practitioners such as Grove in Great Britain and Bellingham, Alvarez and Greenough in Australia have adapted or enhanced their practices to meet the challenge of storytelling for individuals and groups of people with severe intellectual disabilities, and older adults with moderate dementia.

These adaptations focus on creating positive anticipations before, active audience engagement during and positive reminiscences after storytelling events. Successful storytellers for people with SCI are able to enhance the potential value and worth of storytelling events (performances) through: welcoming interaction with the intended audience participants during set-up prior to the event; emphasising and facilitating proactive participation and engagement amongst audience members during the event through skilful ‘reading’ of the audience (Georges); and facilitation of personal and/or collaborative engagement with the storytelling experience after the event via prompted recall, reflection and reminiscence (Grove Ways into Literature). In short, storytellers who are successful with people with SCI intuitively ‘stretch out’ and enhance the positive personal lived experience of the storytelling event for participants; before, during and after the actual event. We call this strategy ‘collaborative stretching’ (Lyons, Cassebohm and Mundy-Taylor).

**Personal and collaborative stretching**

Most of us prepare for favored events in our lives. We plan and organize for these events beforehand, take the opportunity to engage in positive anticipations, and think about
and discuss our positive expectations for these forthcoming events with important others. Most of us also reflect on and reminisce positively about past favored events; privately and/or with important others. We call this very prevalent strategy ‘personal stretching’ (Lyons, Cassebohm and Mundy-Taylor). It occurs when an individual ‘stretches out’ or enhances the enjoyment of a positive lived experience through strategic anticipation, expectation, reflection and reminiscence. Personal stretching can deliver repeated periods of enjoyment for months before an event and repeated periods of enjoyment for months and (even many) years after an event. This enhanced enjoyment leads to enhanced personal happiness, subjective well-being and ultimately (subjective) quality of life (Lyons and Cassebohm; Harmer and Orrell).

Figure 1 provides a graphical representation of the stretching strategy. Stretching, that is enhanced enjoyment, occurs when the experience of and around an enjoyable event is stretched by increased awareness and focus on the activity before, during and/or after that event. Stretching provides positive expectation, anticipation, reflection and reminiscence experiences; from micro (shorter), through macro to even meso (longer) periods. Note: Increasing the duration of an enjoyable event alone will enhance the quality of the experience but this approach is often unavailable.
For example most of us enjoy annual holidays. Although these may only last for a short time, we usually stretch out our enjoyment through positive anticipation and expectation before the holiday, and then through positive reflection and reminiscence once the holiday is completed. More pertinently, most of us enjoy a good storytelling event, either impromptu events which occur naturally as part of our social engagements with others, or as part of planned storytelling events or performances. We similarly enhance our enjoyment of these storytelling events by using personal stretching; rehearsing in our own minds how we will relate a personal narrative or through anticipating what the advertised program may contain for planned events. When we have told a personal story, we consider and enjoy the responses of our listeners, and perhaps adapt the story for the next time it is told. (Gibson). After the planned storytelling event we reflect on and evaluate the stories shared. For people with SCI though who are dependent upon others for their well-being and who have very little personal
agency there are obvious cognitive challenges to using personal stretching to enhance quality of life. These individuals may (be able to) use this strategy but this is very difficult for others to determine (Finnema et al.; Forster). Collaborative stretching, based on the proactive participation of collaborating others, is a facilitative alternative to or enhancement for personal stretching for people with SCI (Lyons, Cassebohm and Mundy-Taylor).

**Personal and collaborative stretching: An evidence base**

The authors acknowledge that personal stretching is not a startling new strategy but rather that it is a very commonplace and intuitive strategy inherent in the human psyche. Most people would readily agree that if we have more time to think about what we enjoy that life is subjectively more ‘rosy’! Theory and research suggests though that people with SCI live more ‘in the moment’ and ‘day-by-day’ (Grove "Telling and Sharing Stories"; Lyons "Life Satisfaction for Children with Profound Multiple Disabilities"; Finlay et al.). It is probable then that they are less adept than most others at using personal stretching to enhance their own positive lived experiences and must then rely upon collaborating others to stretch their positive lived experiences for them. The challenge then arises for these collaborating others to achieve this enhancement (Lyons "Quality of Life for Persons with Intellectual Disabilities: A Review of the Literature").

People with SCI are less able and likely to positively anticipate and expect forthcoming favored events (Barber; Charlton and Sturmberg). This is not to say that they cannot do so but rather that these abilities are likely to be less substantial, practiced and applied. Similarly they are less able and likely to positively reflect and reminisce about past favored events (Barber; Maslow and Heck). Again this is not to say they cannot. The responsibility to identify, build and strengthen these abilities lies with collaborating others. There is a clear imperative to ‘come to know’ the individual with SCI, and to build mutual
skills in communicating about his/her interests, wants, preferences and needs (Forster and Iacono; Vlaskamp, Hiemstra and Wiersma; Porter et al.). As noted by Gibson sharing stories is a highly effective means of building relationships and as Zipes further described, is also effective in building communities. Practising storytellers are well-placed to utilize their skills in ‘reading an audience’ and communicating effectively to facilitate meaning-making and relationship building.

Best practice and best outcomes are more likely to eventuate when they are duly informed by a rigorous theoretical scaffold which has been built upon valid research (Carnaby; Kaiser and McIntyre). The notions of personal and collaborative stretching have been built on a diverse evidence base. The following section explains a summative taxonomy of this evidence and is followed by brief explanations about how this evidence contributes to the development and application of the stretching strategies.

Figure 2 introduces a taxonomy of this evidence base. This taxonomy indicates the diversity of theories, principles and related research which provides the evidence base for personal and/or collaborative stretching. This is not a prescriptive or complete taxonomy but is developmental and summarily suggestive only. Twelve contributory ‘clusters’ of evidence are presented in four groups of application or practice and three levels of contribution.

Evidence has been clustered because they share stronger interrelationships within rather than across groups; in relation to informing the stretching strategies. The evidence has been placed into levels according to its relative strength of contribution towards the development of the stretching strategies. First level evidence has had a higher strength of contribution towards this development, and vice versa. Lower level evidence somewhat underpin higher level evidence in this taxonomy. Notably again, these are not rigid interrelationships but indicative of the ‘sense’ of the taxonomy. In the following section each of these clusters of evidence are summarily described. Readers are then referred to suggested references for more information
if required.

Figure 2. Evidence-based taxonomy

Evidence Cluster A1: Life Satisfaction Matrix Principles / Dementia Care Mapping

The Life Satisfaction Matrix (Lyons "The Life Satisfaction Matrix: An Instrument and Procedure for Assessing the Subjective Quality of Life of Individuals with Profound Multiple Disabilities") is a procedure for enhancing the subjective quality of life of people with profound intellectual and multiple disabilities. It is underpinned by four principles, the most pertinent being “…for people with PIMD life satisfaction is improved when more time is spent on preferred and less time on non-preferred activities…” (p.766). This principle, taken for granted for people generally, was (only) a presumption for people with these disabilities because of their severe cognitive and communicative impairments. Lyons’ earlier research (Lyons "Life Satisfaction for Children") provided an evidence base for this principle.
Collaborative stretching for this group of people with SCI is clearly underpinned by the first part of this principle.

Dementia Care Mapping is a tool for measuring and improving the quality of life and care for people with dementia. It is grounded in a person-centered approach to dementia care and is recognized as ‘gold standard’ practice in the field (although advocates acknowledge its limitations with respect to people with more advanced dementia). Trained observers code changes in the affective behavioral profile of people with dementia during representative times of the day. These changes indicate an individual’s relative state of ill- or well-being when mapped against ‘positive events’ and ‘personal distractions’ (Brooker 11). A review of this data informs carers about how to enhance quality of care, and hence quality of life / lived experiences. Collaborative Stretching for this group of people with SCI relates closely to efforts by carers and service providers to have people with dementia to spend more time engaged in positive (enjoyable) events. [For further information see Kuhn, Ortigara and Kasayka; Brooker; Edelman et al.]

Evidence Cluster A2: Person Centered Planning / Sociological Theories

Person-centered planning principles are contemporary best practices based upon the foundation that people with disabilities must have their individual needs and interests reasonably responded to and accounted for, within broader service requirements. The accepted focus in person-centered planning is on personal goal attainment; based on professional knowledge, attentive care and adequate resourcing, particularly with respect to quality of life matters. Collaborative stretching initiatives which are so dependent upon the collaborative involvement of others, must take individual interests, preferences and needs into account. [For further information see Vlaskamp and Van Der Putten; Lawlor and York; Wehmeyer; Reid and Green.]
Collaborative stretching initiatives for people with SCI also needs to take into account theories which address the reality that these person-centered planning principles are often implemented for groups of people with SCI. Social interaction theory has been a mainstay of social psychology for some decades and has helped to create and maintain a bridge between psychology and sociology theory. More recent sociological theories have extended these theoretical discussions to better account for the interplay between identity and power relations. For people with SCI, with so often depressed social identities and positions (of relative powerlessness) there is a clear imperative for those participating in collaborative stretching initiatives to recognise how their actions and attitudes impact those in their care. [For further information see Bronfenbrenner; Turner; Van Dijk; Hogg, Terry and White.]

Evidence Cluster A3: Quality of Life Principles and Related Research

Quality of life (QOL) has emerged as a broad and popular field of research over the previous thirty years, particularly as it relates to people with disabilities and others marginalized by disadvantage. The broader phenomenon of QOL is consensually composed of objective QOL; akin to standard of living, and subjective QOL; akin to subjective well-being or life satisfaction. Happiness, a key human pursuit, is generally viewed as a more transient emotional state. Nevertheless, enhanced happiness is generally equated with subjective QOL. The claimed pursuit of an improved QOL underpins much of the pertinent contemporary literature around policy, practices and service goals for people with SCI and this is evident in the first two evidence clusters. Highly pertinent here, for example, is Lyons’ grounded theory on life satisfaction for children with profound multiple disabilities (Lyons "Life Satisfaction for Children"). This theory underpins the four principles of the Life Satisfaction Matrix introduced in evidence cluster A1. There is some research about QOL for people with dementia but very little about people with more severe dementia. [For further
Evidence Cluster B1: ITPRA Expectation Theory

David Huron’s ITPRA Expectation Theory is an exemplary theory which provides a key part of the primary evidence base for understanding stretching. Huron draws heavily on cognitive science and evolutionary psychology in his theory on the psychology of expectation to deliver a framework for a five step process for understanding events in terms of individual expectations and response/s. These five steps, divided into two phases are: imagination (I) and tension (T) in the pre-outcome response phase; and prediction (P), reaction (R) and appraisal (A) in the post-outcome response phase. In Huron’s words: “…the most interesting property of expectation is the feeling that can be evoked. What happens in the future matters to us, so it should not be surprising that how the future unfolds has a direct effect on how we feel.” (p.398). This offers a lucid explanation of the importance of the expectation-anticipation-reflection-reminiscence process that occurs around an enjoyable event, and how the experience can be enhanced through stretching. [For further information see Huron; Biancorosso.]

Evidence Cluster B2: Cognitive Behavioral Theories

Cognitive behavioral theories are mainstays of modern human behavioral science theorizing. Amongst these is Albert Ellis’s Rational Emotive Theory. This theory explains a complexity of interrelationships between: feelings (emotions); beliefs (thoughts / cognitions); and behaviors (acts). In short, behaviors, beliefs and feelings are interdependent and influence each other. The principles of Rational Emotive Theory (and similar cognitive
behavioral theories) are closely relevant to the principles underpinning stretching. That is the key significance of the contributions of positive beliefs towards feelings about pending and past positive events [For further information see Dryden; Dryden, Di Giuseppe and Neenan.]

Evidence Cluster B3: Behavioral Learning Theories

Behavioral learning theories are the earliest, most resilient and widely accepted theories for explaining human learning. Significant amongst these is Applied Behavioral Analysis which involves using contemporary learning theory to change behaviors. A key paradigm is the A-B-C paradigm which posits that behaviors (B) are preceded and precipitated by particular antecedent conditions (A), and followed and maintained by particular consequential experiences (C). A critical relationship here is between behavior and its environment. By assessing the functional relationships between these, practitioners are able to change that behavior. A comparison may be drawn between the A-B-C paradigm and the expectation/anticipation - positive event - reflection/reminiscence process of the stretching theory. That is what one does prior to a (positive) event in expectation and anticipation and what does after that event by way of reflection and reminiscence are related. Expectation Theory (see Evidence Cluster B1 above) is also comparable. (For further information see Lyons, Ford and Arthur-Kelly; Alberto and Troutman.)

Evidence Cluster C1: Intensive Interaction

Intensive Interaction is a technique for developing pre-verbal communication and social skills in people with severe intellectual disabilities, as well as for building positive relationships. Practitioners seek to replicate the naturalistic processes of infant-caregiver interactions, an approach which draws closely on the theory and principles of ‘augmented mothering’ as explained by Gary Ephraim. Its main features are: the creation of mutual
pleasure and interactive games; staff adjustment of their behaviors to be more engaging and meaningful for the client; interactions that ‘flow’ in time with strategic pauses, repetitions and blended rhythms; responding to client behaviors on the assumption that they are expressions of communicative intent; the use of contingent responding, that is, following the client’s lead (mirroring) and sharing the conversational lead (Firth et al.). The principles of Intensive Interaction are quite synchronous with those of Storytelling (see Evidence Cluster D1) and its focus on ‘coming to know’ people with severe intellectual disabilities in order to collaborate with them to enhance enjoyment, and clearly informs the practice of collaborative stretching. [For further information see Ephraim; Nind; BILD; Firth et al.; Samuel et al.]

Evidence Cluster C2: Active Support

Active Support is a contemporary proactive and reflective approach to practice in supporting people with intellectual (including severe) disabilities. Active Support aims to increase meaningful and enjoyable engagement in daily activities with a view to enhancing subjective wellbeing and quality of life. Active Support is very closely aligned to Person Centered Planning (see Evidence Cluster A2), and focuses on: assisted participation; the nature of the assistance required (verbal, gestural, demonstrative, physically prompted); proactive (rather than passive) activity engagement; learning in situ; and collaborative cooperation (Stancliffe et al.). All of these stated elements of Active Support are essential in making stretching an effective ongoing activity for those with SCI. [For further information see Totsika, Toogood and Hastings; Stancliffe et al.; Felce, Jones and Lowe; Maes et al.]

Evidence Cluster C3: Behavior State and Attention State Research

The theory and principles scaffolding behaviour state and attention state research underpin much of the evidence-based best practice in Intensive Interaction and Active
Support (as put forward in Evidence Clusters C1 and C2 above). Behavior state and attention research focus on assisting collaborating others to identify and assess the state of awareness/attention/alertness and ultimately readiness to learn (cognitively engage with) the communicative attempts of others. For people with severe and profound intellectual disabilities levels of engagement vary from asleep-inactive to drowsy to awake-active-alert; in social, familial and educational contexts. Clearly unless a person with these disabilities is alert to potential interaction and engagement there is little hope that learning can occur. Research suggests that people with severe intellectual disabilities spend up to half of their time in behavior states which are not optimal for learning (Roberts et al. 89). Collaborative stretching can only be facilitated if more optimal behaviour states are evident and/or have been elicited. [For further information see Arthur; Arthur, Hook and Butterfield; Roberts et al. and Munde; Munde and Vlaskamp respectively.]

Evidence Cluster D1: Storytelling / Storysharing© and Life Story Work

Storytelling is a universal human instrument of drawing meaning from life experiences. (Abrahamson; Barton and Booth; Denning; Sobol; Boyd) By sharing stories with others, whether they are fictional or based on personal experience, we gain an understanding of the effect of these experiences and in so doing build relationships with our listeners (Gibson). Practitioners such as Grove have recognized the significant relationship building benefits of storytelling for people with SCI and developed storytelling presentation styles such as her StorySharing© program to meet the particular needs of her audiences. Storytelling with people with SCI involves significant amounts of planning to ensure that the event incorporates participation which meets the capabilities of the group or individual and uses multi-sensory props and aids to assist with the storytelling. [For further information see Alvarez and Greenough; Grove *The Big Book of Storysharing: At Home, in School*.]
Life Story Work is a principle that meshes well with the principles for storytelling with people with SCI, in addition to taking much of its theory from Person Centered Planning. Used increasingly with older people who have dementia and people of all ages with severe intellectual disabilities it is an activity that relies on the person’s family, close friends and carers to work with the individual in collecting multi-media items that represent experiences in that individual’s life. When combined with facilitated storytelling that gathers the story surrounding each experience and memory, each artifact gains enhanced meaning and significance for the individual. When these items are gathered together in book form they provide a valuable aid to memory, self-awareness and self-esteem. (For more information see (Lloyd, Ritchie and Derwin; McKeown, Clarke and Repper; Gibson; Wills and Day)

Evidence Cluster D2: Reminiscence Therapy, Reminiscence Work and Life Review

The terms Reminiscence Therapy and Life Review appear to be interchangeable throughout the literature (Woods et al.), however Gibson makes a specific distinction between Reminiscence Therapy - used as a means of intervention through focused recollection sessions - and Reminiscence Work, or Life Story Work as outlined above.

While acknowledging the significant value of Reminiscence Therapy (whereby the facilitated recalling of life stories and teasing out their meanings is perceived as a treatment to specifically resolve long-standing personal issues,) that is used in both dementia care settings and in general therapy contexts (Davis; Jones), this paper is concerned only with Reminiscence Work as it applies to stretching, where props and memorabilia can be used as triggers to encourage anticipation, as aids to actual storytelling and recollection, and as mementos in reflection.

Evidence Cluster D3: Validation Theory
Validation Theory (The Feil Method) is widely (but not uncontentiously) recognized as a valuable intervention for older people with (advanced) dementia. The basic principle is the concept of reciprocated communication of respect. Practitioners communicate to the individual that their opinions are ‘heard’ and respected and are viewed as legitimate expressions of feelings and realities rather than being marginalized or dismissed. This recognition occurs regardless of whether or not the practitioner is in agreement. Interactions with people who have SCI resulting from dementia which embrace the primary principles of Validation Theory are likely to enhance attempts to stretch enjoyed experiences. [For further information see Finnamore and Lord; Feil.]

**Storytelling with collaborative stretching: The basic steps**

For a given storytelling performance (event) how can the storyteller stretch (enhance) the experience of the audience participants? How do storytellers collaborate with the audience participants and performance organizer(s) before and after the event in order to facilitate micro-, macro- and/or meso-stretching through the assisted enhancement of expectation, anticipation, reflection and reminiscence?

To adapt / enhance storytelling with collaborative stretching to best engage and advantage people with SCI the following basic steps are involved:

1. Identify a favored (enjoyed) topic relevant to the audience for a planned storytelling event. This topic should be readily able to be ‘linked’ to more frequent activities of daily living. This topic and these contextualizing links are best identified through discussions with the intended audience participants (with SCI) and their collaborating others.
2. Prepare the story outline / script, and any key props. Knowledge of the performance space or venue is useful when determining the number and scope of props that can be used.

3. Develop a collaborative stretching plan for the event by negotiating opportunities for the audience members to spend time thinking around the topic/story/event; both before and after. (Obviously ‘stretching’ the actual storytelling event time would be beneficial but this is not always practicable.) Stretching before the event aims to increase time spent in positive anticipation and expectation. Stretching after the event aims to increase time spent in positive reflection and reminiscence. Cues, prompts and props are often facilitative here. They may be invitations to think about the topic, promotional posters about the booked event, or the placing of actual props related to the event topic in high-traffic areas in the days leading up to the storytelling event. In the days following the event, these cues and prompts may be used to encourage reflection and reminiscence.

4. Monitor the plan’s impact on levels of enjoyment, happiness and subjective well-being a) during the ‘stretched’ periods before and after the Storytelling activity, b) during the Storytelling activity, and c) overall (say daily)

5. Whenever possible encourage the individual to use Personal Stretching i.e. to anticipate, expect, reflect and reminisce about this storytelling activity and other favored activities.

Note:

In acknowledging and accounting for the individual constraints in memory, cognition and expression variously experienced by those with SCI, collaborating others can negotiate storytelling events which are more readily able to be enhanced by collaborative stretching.
This may mean (just) ‘micro’-stretching only seconds or minutes before a storytelling event and/or micro-stretching just seconds or minutes after such an event; the individual’s level of attention and behavior state are critical here. Research does though suggest that the strategic application of stretching just prior to a favored activity can heighten an individual’s ‘readiness’ for and capacity to enjoy this activity (Huron). A sound knowledge and awareness of the individual’s affective indicators of contentment, boredom and frustration are also critical here to avoid the possibility that a well-intended initiative does not invoke boredom or frustration.

**Storytelling with people who have SCI: Four vignettes**

**Story 1: Wild creatures at the school camp**

A four day excursion for a group of students with intellectual disabilities takes place at the regional school camp facility. Some of the students also have physical disabilities. A local storyteller is engaged for one evening’s activity.

After negotiating with the camp’s Education Officer and the school’s organizing teacher, Australian bush animals is selected as a suitable theme for the storytelling event. The storyteller provides the Education Officer with sturdy cardboard cut-outs and stickers of various Australian native animals in the week preceding the camp. From the first day, the cut-outs are placed in unexpected but easily seen spots around the camp: near the water dispenser in the communal dining room, on the windowsill of the office at the entrance to the camp buildings, hanging from the abseiling tower etc. When a student sees the cut-outs (often prompted by a support person) they are given a corresponding sticker. At various times of the day teachers, camp workers and carers ask to see the stickers and share facts with the students about the animal – appearance, noise, food habits etc. In the two days preceding the
storytelling event, staff members talk to the children during meals about the visiting storyteller, and raise the possibility of Australian animal stories.

On the specified evening, the storyteller greets each student and welcomes them all to the storytelling event. Only when each student is present does the interactive set up begin. A simplified tree constructed of ply wood is placed to one side of the storytelling space. A length of shimmering blue cloth is dramatically draped on the floor along the opposite side of the space. A corduroy bean bag is placed near the storyteller’s chair, and ceremoniously thumped until it resembles a bush rock. When all the props are in place, the story of ‘When Gecko lost his tail’ is told. It is a highly interactive story, where the students are invited to identify each animal that assists Gecko in his search for his tail and to dramatise the actions of each animal. As each animal is named the storyteller goes to the appropriate prop with a puppet to tell that section of the story.

In the remaining days of the camp, the students are encouraged to look for the animals from the story in their bush camp setting, and the students eagerly participate and talk about the search with each other and their support staff. By utilizing the assistance of the school and camp staff and preparing props and the program well in advance, the storytelling experience for the students is stretched over several days at least, and an enhanced enjoyment of one simple story is achieved.

Story 2: The Friday movies

As a guardian for adults with intellectual disabilities, I held the responsibility to ensure that paid support services provided care and support which led to the best quality of life for our mutual clients. Four of my clients, each with severe intellectual and other disabilities, lived in a suburban group home with fulltime supervision and support for most of their activities of daily living.
Part of their home program was a ‘Friday Activities’ event when staff took them on a
group outing to different preferred community venues and activities. This was generally an
enjoyable recreational event for all. On return in the later afternoon the clients were invited to
participate in a ‘Reminiscence / Storytelling Session’ wherein they shared stories about their
outing.

As part of the clients’ service program review staff, interested family members and I
discussed the Sessions. Consensus was that they did not enhance or contribute to improving
client enjoyment or quality of life, as evidenced by the residents’ general demeanor and
limited participation in the Sessions. After discussions with all interested parties a range of
initiatives were implemented to enhance the Sessions:

- Monday Weekly Planning Meetings now included discussions about options for the
  following Friday Activities. Pertinent digital photo images, video clips, artifacts and
  explanations were presented to inform decision making.

- On Tuesday clients were reintroduced to their options and then invited to actively
  contribute to decision making about the Friday outing.

- On Wednesday clients were encouraged to discuss and plan any preparation required
  to facilitate the Friday outing. This might include specifically assigned but voluntary
  ‘duties’ prior to and even on the day.

- On Thursday the forthcoming Friday Activities outing was again reviewed, drawing
  upon the content of the three preceding discussions.

- On Friday an assigned staff member made a selective video recording of the
  participants / day activities from the time they began preparations until they returned
  back to the group home. This recording was then presented at the Friday afternoon
break (the ‘Friday Movies’) prior to the Reminiscence Session, along with display of any artifacts collected during the outing.

This range of initiatives clearly enhanced client engagement in and enjoyment of the Reminiscence Session and the Friday Activities outing. Staff and clients now reminisce happily and collaboratively following the Friday Movies showing in the Reminiscence Session, and thereafter. Clients and staff have shown a greater interest in collaborative decision making when planning the Friday outings. Much laughter pervades the Friday Movies and the Reminiscence Session with clients often calling for repeated showings of the movies. Although this range of initiatives took a lot of time to negotiate and takes a lot of time to implement, they have clearly ‘stretched’ our clients’ enjoyment and quality of life.

Story 3: Ahh, the smell of sunscreen
(With thanks to ‘The Tale Spinners’ Sue Alvarez and Christine Greenough for generously sharing their storytelling experiences.)

Two sprightly, flamboyantly dressed women arrive one morning at the Second Wind Residential Care Home for the Active Aged. They note with a smile the mock beach (see Figure 3) that has been constructed in a sheltered corner of the grounds and they have heard so much about. Several residents are relaxing on the sturdy beach chairs scattered about. Our two storytellers proceed to take several boxes of props into the day room then chat with the staff about the final makeup of their audience. Who will be attending, is anyone out of sorts today, is there a topic they should avoid mentioning? When the audience begins to arrive and while unpacking boxes our two storytellers begin a friendly banter that soon effortlessly includes many of the residents as they notice the hats, beach towels and umbrellas
that appear from the boxes. As props appear the storytellers ‘spontaneously’ start to sing related songs from bygone years and soon some of the residents are singing along enthusiastically. The storytellers cease their singing and allow the residents center-stage. When everyone has arrived and sufficient props are unpacked one of the storytellers begins a personal narrative about beachside holidays. She begins to rub sunscreen on her nose and arms, only to be reminded by her friend not to forget the back of her neck like she did last time. A woman from the audience says that her mother always told her to put the sunscreen on her toes. A gentleman from the front nods but adds that people said in his day that a healthy suntan was good for you.

The story continues incorporating memories of exploring the melalucca scrub near the beach. A branch of tea tree is passed around the audience and the story unfolds, prompting other reminiscences of childhood spent in the bush and remedies for keeping the insects at bay. The storytelling continues at a relaxed pace with plenty of space provided for the audience to participate through their own recollections, songs or poems often prompted by multi-sensory props.

When the storytelling event is over and as the storytellers pack up numerous residents linger, recalling their own beachside memories while handling the props that they were keen to look at again. The storytellers give no indication that they are in a rush to get away and chat with each resident who approaches them. They are often touched by the personal stories that are shared in this latter part of the event.

When the residents have moved on to other areas of the facility the storytellers welcome the opportunity to chat with available staff over a cup of tea. They share their ideas about how the event can be further stretched, how similar props could now be gathered by the staff to prompt reminiscences and point out that they focused their program on the beach holiday theme after being told about the mock beach. They later learn with delight that the
beach area becomes a very popular spot for the residents in the days and weeks following their storytelling event with many recollections of beachside adventures shared, and people are observed just digging their toes into the sand wearing smiles of contentment.

Figure 3. Mock Beach at the Second Wind Residential Care Home for the Active Aged

Discussion

This paper has presented what the authors have labelled strategies for personal and collaborative stretching and how the latter might be applied to storytelling to enhance the experiences of audiences of individuals with various severe cognitive impairments. It commenced with a representative example of collaborative stretching, followed by an introduction to severe cognitive impairments and how these impact those with advanced dementia and severe intellectual disabilities. It also briefly explained the ‘intersection’ of storytelling with these individuals and posited that storytelling had broad positive implications for enhancing their lived experiences and quality of life. An evidence-base for these strategies was then put forward, followed by a brief expose’ of the basic steps involved
in implementing collaborative stretching with storytelling. Three vignettes followed as examples of ‘enhanced’ storytelling for people who have severe cognitive impairments.

Personal and collaborative stretching might simply be described as ‘making the most out of a good thing’. Most of the readership would be familiar with personal stretching: it is a natural positive human behaviour. Fewer would be familiar with collaborative stretching; particularly as it relates to storytelling for people with severe cognitive impairments.

Storytelling for people with severe cognitive impairments is not a common practice. This might be because knowledge and familiarity with these people is lacking for storytellers; that these people lack the personal agency to seek out storyteller ‘services’ and/or their support persons do not see value in storytelling for them. It might be because storytellers are reticent to engage because of the communicative hurdles which are likely to come between them and the audience; that they are concerned with ‘doing more harm than good.’

Whatever the case, the authors have sought to empower storytellers to engage professionally with people with severe cognitive impairments. Storytellers are in a unique position to bring enhanced lived experiences to people with severe cognitive impairments because they are ‘in the business’ of communication and relationship/community building and may ultimately bring better quality of life to their audience members. Knowledge of collaborative stretching, and how it might be applied to storytelling to enhance practice and outcomes, would appear to be facilitative.

It is the authors’ view that a diversity of issues need be taken into account and responded to if storytelling is to become more commonplace and more successful amongst this quite marginalised group. These issues are presented in this Discussion section. Some will call on storytellers to review, rethink and maybe modify their personal and professional beliefs about why and how they might tell stories and collaboratively stretch for such an audience. These are referred to as philosophical considerations. Others will call on
Storytellers to review, rethink and perhaps modify their professional practices; that is how they might share stories with such an audience and what they might do to enhance and collaboratively stretch the experience and event outcomes. These are referred to as practical considerations.

Figures 4 and 5 provide graphical representations of ten such considerations and indicate their interrelationships. In Figure 4 seven interrelated philosophical considerations (briefly described in this Discussion section) are represented in three overlapping groups. When all seven have been taken into account and responded to, storytellers are positioned to design, develop and deliver best practice storytelling for people with severe cognitive impairments. In Figure 5 three interrelated practical considerations (briefly described in this Discussion section) are represented in three overlapping groups. When each of these have been taken into account and responded to, storytellers are most likely to deliver best practice storytelling for these people.

<INSERT FIGURES 4 & 5 HERE>

Philosophical Consideration 1: Storytelling audiences: difference and diversity

Storytelling audiences comprised of people with SCI are ‘different’ and diverse. They will (of course) include people with SCI who by nature of their impairments have very individual cognitive and communicative profiles AND their significant others; including variously family and other unpaid carers, and/or professional support persons. Stories will need to be accessible, engaging and enjoyable for this diverse audience. How might you respond to these challenges? What are your beliefs and feelings about and attitudes towards disability, ‘difference’ and diversity? Is storytelling ‘the same’ (in principle if not practice) for all audiences irrespective of age, gender, cultural and linguistic background and/or
dis/ability? How do you reconcile differences between people with various SCI (e.g. severe dementia and severe intellectual disability) with their similarities (e.g. basic human feelings, wants, needs, wellbeing and quality of life)?

*Philosophical Consideration 2: Storytelling styles*

The perennial philosophical discussion about the relative merits or ‘appropriateness’ of traditional storytelling, as opposed to augmented storytelling styles is pertinent. Theory and practice around storytelling (and communication generally with) people with SCI clearly indicates a need. Is your philosophical position on storytelling styles synchronous with this need? Are you comfortable with varying your storytelling styles to address diverse audience interests, wants, needs and capabilities? Is collaborative stretching synchronous with your personal storytelling style?

*Philosophical Consideration 3: Storytelling purposes and ‘sense of story’*

An overarching goal for many storytellers is that their audience engages with the storytelling event / experience and develops a valued ‘sense of story’, while for others it is ‘just’ about enjoyment. The purposes of storytelling can be diverse. These may be: to entertain; to broaden life experiences; to facilitate (philosophical, ethical or moral) learning, growth and development; and/or to improve quality of life. What are the ‘purposes’ (aims, objectives, goals, outcomes) for your storytelling? Do these depend upon the nature of your commission and prior enquiries and/or does audience behaviour ‘on the day’ guide your professional compass?

*Philosophical Consideration 4: Storytelling ethics and responsibilities*
The nature and expectations of professional ethics for storytellers varies widely amongst organizations. Some storytelling bodies have prescriptive codes of ethics; others have none other than the expectation that individual practitioners will develop and adhere to their own code of ethics. For audiences of children it is generally accepted that storytellers (like all professionals engaging with children) have a higher ‘duty of care’ or level of responsibility. Not surprisingly adults with diminished agency / autonomy are generally treated similarly. How do you view your responsibilities to audiences of people with SCI? Do (your) ethics apply equally across audiences or do different standards of responsibility prevail? Clearly, when storytelling with people with SCI, there is a strong professional imperative to acknowledge and respond to increased dependency and greater inequity of power; and this is heightened by the need to get to know and be close to these people to facilitate communication, intersubjectivity and sense of story. This challenge is further complicated by the need to proactively collaborate with important others who provide care and support. Can you reconcile your ethics and practice/s to meet the pragmatic requirements of storyteller/facilitator collaboration?

*Philosophical Consideration 5: Collaborative stretching: contexts*

Many of us engage in collaborative stretching wherein we encourage and facilitate expectation, anticipation, reflection and reminiscence in close others. For people with SCI, who (we believe) struggle to use personal stretching to enhance the personal enjoyment of daily living, collaborative stretching is a responsibility for important others around them. Collaborative stretching is also a potentially valuable enhancement for storytelling generally (and much of the explanations offered in this paper are readily applicable to storytelling for general audiences) but it is, in the authors’ view, a prerequisite for storytelling for people with SCI. Can you ‘see’ validity and legitimacy in the use of collaborative stretching across
these contexts? (How) can you draw on this to inform your use of collaborative stretching in your storytelling?

**Philosophical Consideration 6: Collaborative stretching: foci**

Stretching (within storytelling) can be variously focused on what happens before, during and after the event/performance, and for varying durations: for micro (seconds to minutes) to macro (minutes to hours) to meso (days to years) duration. It varies with respect to intended intensity of experience i.e. the relative degree of ‘weight’ or emphasis given to stretching activity across the experiential time span. (Figure 1 is pertinent here.) Stretching tends to focus on the storytelling ‘experience’ rather than (just) the event/performance. There is however no clear dichotomy with respect to event and experience other than that the event (or performance) can be more readily defined in time, whereas the experience obviously can extend far further both before and after. More so an event is generally a lived sensory / physical occurrence whereas experience, especially outside of the event period, includes cerebral or imaginative experience. How might you (prefer to) vary your use of collaborative stretching across these foci? Are you ‘comfortable’ with this explanation of event and experience and does this illuminate options for preparation, presentation and reflection? How might you balance the needs of different members of an audience for people with SCI? How might, for example, you balance the need for ‘knowing and being close’ to audience members with SCI against the possible professional development needs / expectations of audience members who are carers / support persons?

**Philosophical Consideration 7: Collaborative stretching: the evidence-base**

Stretching, although relatively simple and intuitive, has a diverse and somewhat eclectic evidence-base. This evidence-base may be discussed in terms of its relevance to best
or theory-based practice, as well as in relation to the juncture between theory and practice. Best practice is informed by quality evidence. How valid, rigorous and/or legitimate is the (taxonomy of) evidence proffered in this paper? Is the taxonomy helpful? Can an exploration of aspects of this evidence-base inform and improve your storytelling and/or use of the collaborative stretching strategy (for this and other audience groups)?

**Practical Consideration 1: Storytelling styles**

When engaging in storytelling with people with severe cognitive impairments, a multisensory approach is crucial. While traditional storytelling that uses voice and gesture only to convey a story is both powerful for audiences and personally gratifying for the teller, it will fail to engage an audience with SCI. An augmented style of telling that incorporates touch, participation, smells, dramatisation and other multisensory elements is required to effectively communicate with this particular audience. Is an augmented storytelling style compatible with your own established storytelling style? Can you feasibly adapt the tried and tested stories in your repertoire to incorporate multisensory elements? Do you have storytelling resources (including other storytellers) available to you who can aid you in developing stories in the augmented style? Do you need some coaching from experienced storytellers who are successfully storytelling with people with SCI?

**Practical Consideration 2: Practice collaboration**

The nature of contemporary storytelling often involves a singular event, where the storyteller is booked to share stories with a defined audience for a specified period of time. For many storytellers this event may only be one in a series of visits to various venues in a particular day. The authors contend that storytellers have a responsibility to communicate in the most effective way possible with their audiences, and while costs and time involved in
Practical Consideration 3: Event evaluation

The authors believe that there is no such thing as failure with collaborative stretching incorporating storytelling for people with SCI. There are only strategies that are a resounding success and others that need review and evaluation to make them a more satisfying experience for all involved. Are you prepared to seek and accept feedback from a number of audience members, including both those with SCI and their support persons? This may be in the form of immediate feedback but are you also prepared to formally seek feedback in writing? Are you informed sufficiently about the impairments of individual audience members to be able to gauge their immediate responses to your stories? When a storytelling event ‘feels’ like it has been successful, are you prepared to critically analyze it, against what you know about the needs of people with SCI, to determine those elements that worked?
Likewise, are you prepared to critically analyze those storytelling events that did not meet your expectations for success? Are you prepared, after developing a story, incorporating all of the theoretical and evidence-based elements discussed previously in the paper, to discard a story when it does not meet the most important criteria of all: your enjoyment of it?

Conclusion

Storytelling is a valuable experience for all people but has been used infrequently with people who have severe cognitive deficits. Its use with and efficacy for these people can be enhanced with collaborative stretching which requires their significant others to plan for extending the enjoyment potential of storytelling events/experiences by facilitating and encouraging positive anticipations, expectations, reflections and reminiscences. Although simple in principle, the nuances of planning, implementing, monitoring and evaluating storytelling with collaborative stretching for those with severe cognitive impairments are significant. The creation of positive anticipations, expectations, reflections and reminiscences requires a considerable knowing, intersubjectivity and attunement, and lack of attention in this regard risks boredom and even frustration for some members of the audience. We strongly encourage you to embrace collaborative stretching as a valuable and efficacious strategy for enhancing storytelling for those so challenged by their impairments.

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