Background

A number of terms and definitions have been used to describe people with profound intellectual impairments and the associated disabilities that they frequently experience; profound intellectual and multiple disabilities (e.g. Hostyn & Maes, 2009; Mansell, 2010), profound multiple learning disabilities (Emerson, 2009; Nakken & Vlaskamp, 2002), profound and multiple learning disabilities (Jones, 2005, Ware, 2004). Whilst there may be subtle distinctions between these terms, no such differentiation will be made in this paper, and we will use *profound and multiple learning disability*, and the acronym *PMLD* for consistency.

Definition

At the conclusion of an innovative consensus study, Bellamy et al. (2010) suggest the following components as defining PMLD: extreme delays in intellectual and social functioning, limited verbal skills but responsive to environmental cues, dependence on familiar others to interpret communicative intent, frequent associated medical, physical or sensory impairments. Among these additional difficulties experienced by children and adults with PMLD are visual impairment (often cortical) experienced by 85% (van Splunder et al., 2003), hearing impairment, affecting 25-35% (Evenhuis et al., 2001) with additional challenges in obtaining appropriate audiological services (McCracken and Turner, 2012), and epilepsy diagnosed in 50% (Lhatoo & Sander, 2001). People with PMLD, especially those who were born prematurely, may have a condition called

periventricular leukomalacia, which can cause visual processing difficulties (e.g. Fazzi et al., 2009), as well as gross motor problems (e.g. Fetters et al., 2007) and epilepsy (e.g. Gurses et al., 1999). These children and adults experience difficulties in making use of the incoming visual information.

Prevalence & Heterogeneity

PMLD is a description rather than a diagnostic category but pupil census data from England in spring 2010 (Glover, Evison & Emerson, 2011) has 1.2 per 1000 children between 7 and 15 years recorded as having PMLD. Estimated figures from Emerson (2009), suggest that, due to demographic changes and medical intervention, the number of adults with PMLD in the UK will increase by 1.8% per annum to 2026.

Given the variety and multiplicity of impairments, and the diversity of causes (e.g. chromosomal anomalies, degenerative conditions, infection, perinatal brain damage), within a low prevalence, people with PMLD can be seen to be a relatively small and heterogeneous group (Nakken & Vlaskamp, 2002).

Communication

Impairments in speech, language and /or communication, and a consequent need for intervention, are identified by many researchers (e.g., Bellamy et al., 2010; Iacono et al., 2009; Mansell, 2010; Nakken & Vlaskamp, 2002; Ware, 2004) and in curriculum documents (e.g. Welsh Assembly Government, 2006). The communication abilities of this group are described primarily presymbolic or protosymbolic, including many

idiosyncratic and subtle behaviours which communication partners use context and prior knowledge to interpret (Grove et al., 1999; Hostyn et al, 2010).

Factors that have been identified as important in facilitating communication in people with PMLD include initiation of activity (e.g. Lancioni et al., 2005; Mellstrom et al., 2005) and tactile methods that can aid joint and shared attention (Hostyn et al., 2011). Research findings have indicated that interactions with others are highly important for quality of life (Petry et al., 2005), in particular, sensitive contingent responding by interaction partners (Forster & Iacono, 2008). Parents have been found to be very aware of their child's communication style, using this to maintain interaction (Wilder, 2008) and consistent behavioural repertoires by people with PMLD can be interpreted by communicative partners as conveying affective states (Petry & Maes, 2006). Despite this, evidence suggests that staff do not adjust their language to meet the needs of people with intellectual disability (Healy & Noonan Walsh, 2007) though they reported that it was important to do so. Care staff working with adults who show behavioural challenges tend to infer communicative intent for all behaviours (Bradshaw, 2008). Having a positive attitude towards communicating with the person with PMLD has been found to be an important contributory factor which may influence staff responding (Goldbart & Caton, 2010; Windley & Chapman, 2010).

The existing evidence base

Despite some criticisms (e.g. Burton & Chapman, 2004), health, education and social care professionals are increasingly being expected to implement interventions for which

there is some evidence of effectiveness (Nail-Chiwetalu & Ratner, 2006; Vallino-Napoli & Reilly 2004). Although, as McCurtin and Roddam say (2012, p.11) "there appears to be a conflict between the demands for clinicians to be evidence-based practitioners and the actual use of research evidence in practice". A pragmatic definition of evidence-based practice, particularly useful in areas where research evidence is limited, is given by Sackett et al. (2000) as *the integration of best available research evidence with clinical expertise and patient values*. All three components merit consideration (Roulstone, 2011).

The UK's Royal College of Speech and Language Therapists' Clinical Guidelines (Taylor-Goh, 2005) and ALD Position Statement (Baker et al, 2010) argue that speech and language therapy should be available to people with PMLD, but the evidence base for intervention in this client group is weak and fragmented (Maes et al, 2007; Snell et al., 2010). The present study explores the extent to which SLTs working with clients with PMLD use each of the three aspects or EBP; research evidence, clinical expertise and the views of clients and their representatives, to inform decisions regarding intervention. What evidence exists will be reviewed below.

Empirical Evidence Supporting Communication Intervention for People with PMLD

Reviews (Goldbart, 2005; Goldbart, 2011; Goldbart & Caton, 2010) identified several communication intervention approaches for this client group, for which some measure of evidence or theoretical support was available. Intervention approaches were those utilising *Intensive Interaction*, *objects of reference*, *creative arts therapy, micro-switch*

technology, symbolic approaches and approaches involved either *environmental support and modification* or *staff training*. A brief summary of the evidence supporting each of these approaches is presented and evaluated below.

Intensive Interaction

Small scale, predominantly practitioner research studies have expanded the evidence base in recent years from the original evaluation by Nind (1996). It is established that intensive interaction can lead to positive changes in observable behaviour related to interaction or social engagement (Leaning & Watson, 2006; Zeedyk et al., 2009). Fifteen papers covering 17 studies were identified in a recent systematic review by Drysdale (2011/12), who found that although participants in these small scale studies demonstrated improvements in target behaviours (typically social and communicative behaviours, including initiation and maintenance of interactions interaction) only one third of the studies showed improvement for all participants and targeted behaviours. Moreover, Samuel et al. (2008) report that care staff find it hard to embed intensive interaction in service users' daily routines.

Objects of Reference

This approach was originally designed for use with people with dual sensory impairment (van Dijk, 1989). In 1995 Park considered their use with a wider range of children, finding a dearth of research evidence. Almost 20 years on, there is only one formal evaluation of this approach, or indeed other uses of object cues for communication for

children or adults with PMLD: Jones et al. (2002). This small quasi experimental study showed showing modest success with adults with PMLD.

Creative Arts-based approaches: Narrative

Within this category we have included sensory stories, multi-sensory stories, social stories and other related approaches. With clients with PMLD, the multisensory aspect to the narratives is particularly identified (e.g. Penne et al., 2012; Ten Brug et al., 2012). The evidence base is small but developing, typically comprising small-scale studies (e.g. Ali & Frederickson, 2006; Mitchell & van der Gaag, 2002; Young, 2011). Whilst Young's (2011) multiple baseline design study showed positive changes, a series of papers (e.g. Penne et al., 2012, Ten Brug et al., 2012, Ten Brug et al., 2013) identify process challenges in the implementation of multisensory storytelling.

Creative Arts-based approaches: Music

Whilst based in the Music Therapy tradition, Watson (2007) and Warner (2007), suggest a relationship between their approach and Intensive Interaction. The research base is modest, involving small scale, largely descriptive case studies (Graham, 2004; Perry, 2003). These authors make explicit links between the nature of music and aspects of communication and language to justify the use of music in communication intervention. Whilst this work is limited at present, approaches and tools developed and evaluated for people in 'low awareness states' (Lancioni et al., 2008; Magee, 2007) may also be useful for people with PMLD.

Switch-based interventions

People with profound impairments can learn to use micro-switches to make and convey choices (Lancioni et al., 2006 a & b) and to gain the attention of other people for social contact (Lancioni et al., 2009). This approach has quite a solid evidence base, comprising multiple baseline designs with, typically, small numbers of iterations, mainly from a single group of researchers. According to Mansell (2010), switch-based interventions such as head-switch operated electric wheelchairs, enabling users, for example, to approach others for initiating interaction are still not widely used by practitioners in the UK.

Symbolic approaches

Whilst the use of symbols with adults with more moderate to severe learning disabilities is quite well documented (see, e.g., Beck, Stoner and Dennis, 2009), we found no specific reference to the approach with children and adults with PMLD although the definition of PMLD used in this paper does not preclude some level of symbolic functioning.

Staff Training programmes

The importance of staff interactions with clients has been clearly identified in papers by Forster and Iacono (2008) and Hostyn and Maes (2009). Intervention studies include both multiple baseline designs and small group designs. Whilst most studies report changes in staff behaviour, changes in client behavior are less commonly reported. Recent research on staff training has demonstrated that video feedback can increase staff-client interaction

(Damen et al., 2011). Bloomberg (2003) utilised a 6 month informational and goal focused communication training package with carers, and found limited attitude and knowledge changes but improved carer initiation and responsiveness. Staff could learn a core sign vocabulary (Chadwick & Jolliffe, 2008), but few staff used the signs regularly with clients. Of use here could be Koski's (2010) finding around the importance of establishing new thinking as well as new practices.

Environmental Support and Modification

This approach involves changes made to the events, available activities and resources in client's immediate environment, sometimes through experience of special multisensory environments such as Snoezelen®, with the aim of providing greater opportunities for communication or at least engagement with people, objects and events. Generally, evidence on the impact of environmental modifications has not been positive. Studies show "inconsistent effects of Snoezelen® environments on observable behavior, generalization of behaviors, and relaxation" (Botts et al., 2008, p.138), with researchers concluding that more research is needed (Botts et al., 2008, Stephenson & Carter, 2011; Vlaskamp et al., 2003).

Communication Passports and related approaches

Communication passports are formats for gathering and sharing information about the person and all aspects of their communication. It is debatable whether they are interventions, as such, but their preparation may enhance the knowledge of staff working with the individual, and their use may promote interaction with people around them.

There are many descriptive accounts of their use (for example, Ashcroft, 2002; Millar and Aitken, 2003), but no formal evaluations.

Summary of evidence

Using Eccles and Mason's (2001) grading scheme, none of the intervention approaches described above could be considered to have Grade A evidence for this client group. Only switch-based interventions can clearly demonstrate Grade B evidence, though Intensive Interaction and Narrative approaches are starting to accumulate the required weight of evidence. At present, the remaining areas would be regarded as demonstrating only Grade C evidence, supported primarily by expert opinion and clinical experience.

Client views and values

Ascertaining individual service user's preferences is difficult with clients with profound impairments (Ware, 2004) though some research studies do seek social validation from, for example, parents (the challenges are discussed further in Goldbart & Marshall, 2011). SLTs' and carers' perceptions of what the client wants or needs, or the client's engagement or apparently willing participation could be taken as a proxy for some kind of assent from the learners themselves, but this area deserves further research as it is currently understudied and anecdotal.

Clinical Expertise

The third component, clinical expertise, concerns the way in which clinicians, in this case SLTs, use their accumulated clinical experience to inform their decisions regarding practice. Justice (2010) describes this matrix of theoretical knowledge and practical experience as "craft-based knowledge."

McCurtin and Roddam (2012) have summarised the research from a number of studies (e.g. Brener et al., 2003; Nail-Chiwetalu & Bernstein-Ratner, 2007; Reilly et al., 2004; Zipoli & Kennedy, 2005) concluding that the majority of speech and language therapists do not draw on research evidence to support their clinical decision-making. Rather, a study by Zipoli and Kennedy (2005) in the USA suggests that their primary sources are their own clinical experience and the opinions of colleagues. Phelvin (2012) and Nind and Thomas (2005) provide valuable discussion of the "tacit and intuitive skills and knowledge" (Phelvin, 2012, p. 36) acquired through experience with this client group in learning disability nursing and education respectively.

Summary & Rationale

Currently, it is unclear to what extent each of these approaches is used by SLTs in the UK. Also unknown is the extent to which decisions regarding choice of intervention approach is influenced by EBP, in terms of research evidence, client and other stakeholder preference and clinical experience. Further information on the use and rationales underpinning communication intervention for people with PMLD would allow better investigation and dissemination of approaches that have the greatest support for their effectiveness in the extant literature. It would also inform the direction of research

aimed at investigating the effectiveness of newer or less well researched approaches. Ultimately, the aim of this study is to provide information to help maximise the positive impact of communication intervention on this vulnerable group of people.

Research questions

A survey was developed and distributed to Speech and Language Therapists (SLTs) to address the following research questions:

1. What communication intervention approaches are most commonly used by SLTs working with children and adults with PMLD?

2. What rationales do SLTs give for the selection and use of these intervention approaches?

3. To what extent do the rationales given by SLTS for decision making around intervention selection equate to the EBP framework?

Method

Design

This exploratory investigation used a survey to gather descriptive information from SLTs about their current practice, their utilisation of the existing evidence base and their theoretical knowledge regarding communication intervention for children and adults with profound and multiple learning disabilities.

Survey Development & Piloting

The design of the survey was informed by discussion within the International Association for the Scientific Study of Intellectual Disability (IASSID) Special Interest Research Group on profound intellectual and multiple disability, consultation with experienced speech and language therapists, and the literature on survey design. The survey comprised sections asking questions about (i) The assessments SLTs use (The findings from this part of the survey will be disseminated elsewhere); (ii) The interventions SLTs use; (iii) Background information about the respondent SLT, their experience and the client group(s) they work with; and (iv) The type of service and settings in which they work. Information collected in the survey about the interventions incorporated the types of interventions used, SLTs' rationales for using each intervention, whether each type of intervention was used with clients who were adults, children or with both, and their ratings of the effectiveness of the intervention with these clients with PMLD. Prior to distribution, the survey was piloted by three experienced SLTs currently working at Manchester Metropolitan University. As a result changes were made to minor aspects of the survey's appearance to make it more intuitive to complete. No changes were deemed necessary in relation to the content of questions.

Sampling & Recruitment

Purposive non-probability sampling was employed in the study with the goal being for all SLTs working in the UK with adults and/or children with PMLD to participate in the study. In order to maximise take-up, participants were contacted through the following routes: (i) The Royal College of SLT (RCSLT) circulated a letter to the PMLD Special

Interest Group (SIG) with a letter briefly describing the project and inviting interested

SLTs to contact the chief investigator (CI) for further information; (ii) the RCSLT

published the same recruitment letter in its monthly bulletin; (iii) RCSLT included

information on the project in its CPD e-newsletter inviting SLTs to contact the CI for

further information; (iv) Participants were also asked to forward the survey on to any

other colleagues they knew who worked with the relevant clients groups, thus snowball

sampling was also utilized.

Participants

Fifty-five SLTs working with children and/or adults with profound and multiple learning

difficulties in the United Kingdom completed the survey. Participants represented all

except two of the UK Higher Education Institutions (HEI) with qualifying programmes.

Experience of working with people with PMLD

Fifty-three respondents indicated how many sessions they worked each week. Most

worked full time (35, 66.0%) doing 10 sessions per week (where 1 session = half a

working day), some worked 4-5 days covering 8-9 sessions (6, 11.4%), with the

remainder working 3 to 7 sessions per week (12, 22.7%).

Forty participants reported on the number of sessions they worked specifically with

people with PMLD. Although all the respondent SLTs worked with either children or

adults with PMLD, none of them worked with this client group on a full time basis, with

most working between 1 and 4 sessions per week (24, 60%). Just over a quarter of those

who responded (14, 35%) worked with this client group for less than one session per week and only two (5%) SLTs reported working between five and eight sessions per week with people with PMLD.

Fifty-two respondents reported on how long they had been qualified, and provided ratings of their own experience of working with people with PMLD. Almost half of the respondents (23, 41.8%) had been qualified and working with clients for 10 years or more, with an additional 14.5 per cent (8) qualified for between 6 and 9 years. Over a quarter (14, 25.5%) of SLTs who completed the survey had worked for between 3 and 5 years. Only 12.8 per cent (7) had worked for 2 years or less.

With regard to self-ratings of experience, most of the SLTs rated themselves as either experienced (22, 42.3%) or very experienced (23, 53.8%). Only a few reported that they had limited (2, 3.8%) or some (5, 9.6%) experience. Similarly the SLTs rated their level of expertise in working with people with PMLD as mainly skilled (25, 48.1%) or very/highly skilled (16, 30.8%). A small but evident minority rated themselves as having limited (5, 9.6%) or only some (6, 11.5%) expertise.

Collaborators
Fifty-four respondents reported on the groups they collaborated with in their work. Of the other stakeholders with whom the SLTs collaborated, the most frequently identified group were physiotherapists (43, 79.6%), occupational therapists (41, 75.9) and family carers (41, 75.9%). In addition, more than 50% of SLTs reported working with

psychologists, teachers, SLT assistants, learning support assistants, day and residential staff and dieticians. Other groups they worked with included social workers/care managers (7,12.9%); specialist, nursery & school nurses (5, 9.25%); psychiatrists (3, 5.5%); behavioural specialists; paediatricians; medical officer; special educational needs coordinator (SENCO); play specialist; school tutor; sensory support coordinator; respite staff; portage worker; racial minority link worker; music therapist; "Seeability" worker (provides support to those with profound cognitive and sensory impairments) (all 1, 1.9%)

The great majority of participants worked in Learning Disability Teams (28, 51.9%) and/or Primary Care Trusts (26, 48.1%). Fourteen (26.0%) worked in education settings. Other workplace service settings identified included Challenging Behaviour and Mental Health (dual diagnosis) teams.

Although the range and numbers of collaborators reported by respondents indicate that decision making regarding the introduction of communication interventions for this group is often a multidisciplinary one, it was not possible, given the small sample size and nature of the questioning, to determine the nature of involvement of each group in the decision making process, nor who leads decision making in different contexts. This remains a question for future research studies.

Procedure

Ethical approval for the study was gained from South West 1 REC (Ref: 08/H0203/119). Once this had been gained, RCSLT was contacted to distribute the advertisement to potential participants. SLTs who contacted the first author about the study were sent a package of information including: (i) An introductory letter explaining the study background and objectives; (ii) An information leaflet describing what would be expected of participants and the process for responding (iii) A consent form; and (iv) The survey. A contact number and e-mail address was given in case participants required further information; none did. Participants were informed that they could withdraw with their data from the study at any time, without giving a reason.

Participants were asked to return the surveys within three weeks via email or, if they preferred, by post. Any contact details and the consent form were separated from the survey by an administrator and the survey section was forwarded to the project team. Surveys were given a code number and data were entered into SPSS on a password protected computer. Paper survey responses were kept in a locked filing cabinet, separate from participants' contact details. A follow up reminder e-mail was sent after one week.

Data Analysis

Quantitative data in the surveys were analysed using simple descriptive and comparative statistics. Comments which were difficult to understand, incomplete, or vague were excluded from the analysis. For qualitative data gathered using open questions, conceptual content analysis was used (Carley, 1990). This involved grouping the

rationales by similarity of response, with the proportion of respondents fitting each

rationale being reported. The rationales identified in the content analysis were reviewed

and grouped using the process of thematic analysis. This process incorporated

familiarisation with the data, searching and coding of the text to identify themes within

the data, and reviewing and confirming final themes, as laid out by Braun and Clarke

(2006). Initially the EBP triad was used as a framework for this analysis, subsequently

this was extended and expanded as some rationales did not thematically conform to the

triad. Codes were not mutually exclusive as reports often incorporated more than one

kind of influence.

Findings

Interventions used

A full list of the interventions used by survey respondents with the two client age groups

is presented in Table 1. The majority of interventions were used with both children and

adults. By far the most commonly cited intervention approaches were Intensive

Interaction and Objects of Reference. The approach with the most evidential support,

microswitching, was reportedly used by only 10.9% of respondents. Intensive Interaction

is more often used by SLTs working with adults with PMLD (>90%) but is also very

commonly used by those working with children (79.3%). Communication passports were

used much more frequently with adults than with children, and this difference was

statistically significant (X^2=6.43, df=1, p=0.01). Symbolic interventions were used

significantly more with children (X^2=4.49, df=1, p=0.034), and Creative arts approaches were used only with children.

Insert Table 1 about here

Rationales for intervention use

The rationales are presented below as described by the respondents in their basic theme format for each of the interventions. The basic themes were grouped into organising themes, equating to a revised EBP framework, which will presented below. The extent to which each of these organising themes was mentioned in relation to each intervention can be seen in table 1.

A typology of rationales

The areas identified in the content analysis of rationales were reviewed and thematically analysed, initially based on the EBP triad (i.e. Client/carer view and values, Clinical experience and Research Evidence). Some rationales did not conform to the triad, however, so the framework was expanded into a broader typology. This generated a typology of eight categories of rationale organized under four headings. These were:

1. Research evidence

    1.1 Published research evidence

2. Clinical expertise

    2.1 The views of other professionals

    2.2 Familiar theory/approach that has worked before

3. Individual developmental needs and client/carer views

    3.1 Empowerment, development and behavioural preferences of the client

    3.2 Development of the communication environment and family and carer skills

    3.3 Staff and family views & wishes

4. Practical & Organisational issues

    4.1 Resources available and ease of use

    4.2 Opportunities / restrictions imposed by the context

The presence of each category as reported in the rationales given by respondents for each intervention can be seen in table 1. The coding of the rationales is indicated within each intervention approach in square brackets (below). This typology provided insights into the rationales that mapped onto the particular interventions used with people with PMLD, and will be discussed.

Intensive Interaction

The majority of SLTs (27 of 42) who gave a rationale for using Intensive Interaction cited its role in establishing the foundations of interaction skills and social relationships in those who were often socially isolated or difficult to engage [3.1]. Also commonly cited (13 of 42) was its use in the development of early communication skills [3.1]. Four SLTs specifically mentioned the value of Intensive Interaction with clients who show challenging behaviour [3.1].

Some suggested (11 of 42) that Intensive Interaction was easily used across service settings and was straightforward to implement, requiring no physical resources [4.1].

Four SLTs, however, cited constraints on the use of Intensive Interaction relating to managerial support [4.2], staff availability [4.1] or staff commitment [3.3].

For some SLTs (6 of 42) an important additional component was the enhancement of the interaction skills of staff which came with training and use of Intensive Interaction [3.2]. Five SLTs identified the availability of research supporting the effectiveness of Intensive Interaction [1.1] with a further three referring to its theoretical [1.1] or philosophical [2.2] basis.

Objects of Reference

One or more rationales for the use of Objects of Reference were given by 36 of the SLTs. SLTs articulated why they used Objects of Reference solely in relation to client factors [all 3.1]. In particular, they were seen as helping learners to anticipate or predict what was going to happen next, thus facilitating transitions and reducing any attendant anxiety (16 of 36). For a small number, this was formalised into the use of visual timetables or longer routines (5 of 36). They were also viewed as important for supporting the learner's understanding-in-context, which for some learners, would develop into comprehension (14 of 36). They were quite commonly used to support learners to make choices (10 of 36) and were viewed as supporting learners' transition to more formal means of communication and expression (5 of 36). The importance of Objects of Reference for learners with sensory (specifically visual) impairment was identified by some SLTs (9 of 36).

Multisensory Approaches

Ten of the 21 respondents who mentioned this approach said that it can provide a vehicle for individualised learning for clients through alternative channels of interaction with the environment [3.1]. These allow for increased opportunities to work on improving receptive and expressive communication skills and related cognitive abilities (i.e. anticipation, prediction, exploration, motivation and cause and effect) and for many SLTs, can incorporate the principles of Intensive Interaction demonstrating overlap between these two forms of intervention. Four participants gave as a rationale that it can also target the modulation of sensory information, so as to map on to the sensorial responsivity and requirements of the individual [3.1]. Five stated that the approach provides staff with increased structure and meaning in their interactions with clients, thus training staff [3.2], while empowering individual clients to increase their response rate and to make choices [3.1].

Communication Passports

The core use of communication passports (and thus the main rationale) is shown to be around times of transition between systems, places and people (8 of 16) [3.1]. The passports function to share client-centred information promoting consistency and shared responsibility for communication with individual clients (6 of 16) [3.1]. This client-centredness, inherent in this approach, was also described by three SLTs as empowering people with PMLD and their communicative partners [3.1]. Involving significant others, key workers and key communication partners has shown an increase in carry-over and sustainability of communication approaches (3 of 16) [2.2]. The majority of the respondents provided a rationale linked to behaviours as this method enabled better interpretation of the person's communicative behaviours and reactions that may not be

obvious (8 of 16) [3.2]. These can be interpreted more accurately across contexts, and information is recorded and less likely to be lost between systems (1 of 16) [3.2]. One participant also mentioned that there are cost-effective benefits to using low-tech aids such as communication passports which accords with organisational policy (1 of 16) [4.2].

Symbolic Approaches

A range of signing, symbol and representational systems were listed in response to this section. These included Makaton, Signalong, PECS, objects and photos. Other participants mentioned 'symbols' but did not specify the source from which they were taken. The biggest positive feature and rationale for symbol use was the empowerment of clients through choice making (5 of 15) [3.1], involving both receptive and expressive language skills (8 of 15) [3.1]. One SLT commented on the importance of symbol use for the initiation of communication by clients [3.1]. The fact that symbols are versatile and able to be used alongside other systems and approaches (e.g. Total Communication, other low-tech strategies not specified) was mentioned by four SLTs [4.1]. Three therapists found the approach easy to access [4.1] and, in their experience, the visual focus was easy to implement and highly motivating for clients with sufficient vision [2.2].

Training

Although occasionally mentioned in relation to other interventions, for training and environmental support there seemed to be a clear distinction between rationales related to the processes and outcomes of training for carers and the process and outcomes for

people with PMLD. Hence rationales relating to the two groups will be distinguished here.

There were three main rationales relating to those supporting people with PMLD these were (i) to provide carers with appropriate, individualised, consistent ways of being and communicating with people (6 of 15) [3.2]; (ii) to raise awareness and increase the knowledge staff have about how to communicate with people with PMLD (6 of 15) [3.2]; and (iii) to enable staff to provide more opportunities, write appropriate care plans & devise appropriate sessions for people with PMLD (3 of 15) [3.2].

Two rationales relating directly to people with PMLD were given. One rationale was to develop communication skills and offer opportunities for communication for the person with PMLD that staff could provide following training (1 of 15) [3.1]. A second rationale was that the therapist felt that training was the most useful approach as direct intervention was not possible with the particular client (1 of 15) [3.1].

Only one therapist reported using staff training in conjunction with other interventions and that this approach has an evidence base to support it (1 of 15) [1.1] .

Environmental Support and Modification

Therapists (N=15) described five rationales for environmental support or modification, including multisensory environments. Some stated that they used it because it was powerful at effecting change for people with PMLD (3 of 15) [3.1]. By this respondents

were referring to the ways that by altering the environment this could effect real change in people's lives enabling them to be engaged in communication and included more. Two (of fifteen) said it could aid people's understanding of their environments and could help develop anticipation [3.1]. Environmental support was also reported to provide opportunities for people to develop intentionality/cause and effect understanding (6 of 15) [3.1]. Five SLTs highlighted environmental support as a beneficial intervention because it can be adapted and individualized to the person [3.1], can benefit the most people, and is time and resource effective (1 of 15) [4.1].

With regard to carers, environmental support was said to help carers understand both how to communicate with people with PMLD (4 of 15) [3.2] and also enhanced carer understanding of the comprehension level of those with PMLD they supported (4 of 15) [3.2].

Two therapists stated that it is essential because the day-to-day environment is the barrier to communication [3.2] and past experience of its utility was a rationale given by one [2.2].

Working with Switches
There was strong consensus over the rationales for switch-based work, again relating to client need [all 3.1]. SLTs used switches to teach cause and effect (5 of 6), thus establishing intentionality and environmental control (3 of 6). For the majority of respondents, it was a route to either intentional communication (where the switch might

operate a buzzer to attract others for social interaction) (3 of 6) or increased participation and interaction (for example, switch-operated device for playing a short message) (2 of 6).

Creative arts

Very few participants identified using creative arts as an approach to communication intervention with people with PMLD. In all five cases, this was music. There are reported benefits in terms of multidisciplinary working (3 of 5) [2.1] and also in the value of combining it with other approaches for example Intensive Interaction (3 of 5) [2.2]. Using music does not rely on language but proved to be stimulating for children's language development, motivating for spontaneous interaction and fun (3 of 5) [3.1].

Consideration of rationales

By far the most prevalent rationale given for most of the interventions related to the empowerment, needs, development and behavioural preferences of the person with PMLD. This was mentioned in relation to all interventions, though least often for training which was related most to other stakeholder groups (i.e. staff /family).

Developing carer or family skills and the communicative environment were mentioned in relation to all interventions except for objects of reference, symbolic interventions, working with switches and creative arts. This may be because these are direct, "hands-on" interventions. As would be expected, for training and environmental interventions, developing the communicative environment and partners surrounding the person with PMLD was a key rationale underpinning the decision to implement such interventions.

This rationale was also often mentioned in conjunction with introducing communication passports.

Interestingly, the views and wishes of the family and direct carers were seldom mentioned by SLTs as a rationale for any specific interventions, only being mentioned in relation to intensive interaction. The views of other professionals were only mentioned in relation creative arts based interventions. This is likely to be because the SLTs typically would not lead on such interventions and would rely on other professionals such as art or music therapists.

Clinical expertise in terms of experience and theories that the therapists were familiar with and have seen work were mentioned occasionally in relation to a number of interventions. Though given the primary role this has in underpinning clinical decision making (Zipoli & Kennedy, 2005), it is surprising how seldom it was mentioned

Published research evidence was a rationale cited by respondent SLTs only in relation to intensive interaction, staff training and creative arts. Although these approaches do have empirical evidence supporting them (see above), so too do other interventions (most notably switch-based approaches), Thus the findings here suggest a distinct disparity between the available evidence and that used by the respondent SLTs. In terms of selecting interventions based on an empirical evidence base, whilst intensive interaction, the most often used, has several formal published evaluations, the second most often used; objects of reference, is evaluated in only one published paper. Further research, utilising interviews or focus groups would be valuable in exploring with SLTs why evidence is not being used, although possible reasons are discussed below.

A new group of rationales was developed from the responses that fell outside of the traditional EBP framework, extracted during the thematic analysis; both relating to practical or organisational issues. First, the ready availability of resources for intensive interaction and symbolic interventions and their ease of use were given as reasons for use. Second, the opportunities and limitations imposed by the organisation & service structure within which the SLTs worked was also mentioned in relation to intensive interaction.

Intensive interaction was the intervention with the broadest range of rationales given for its use. The primary reasons for the other interventions typically related to one to three of the typologies (see table 1).

Discussion

A range of interventions were used by SLTs with children and adults with PMLD, with use of intensive interaction and objects of reference reportedly most commonly reported. The extent of reported use of symbolic communication interventions might be considered surprising, but there is no sharp distinction between clients with severe and profound cognitive impairments. As the definition of PMLD used above indicates, whilst these clients are typically pre-verbal, they may not be pre-symbolic. Thus, these symbolic intervention approaches would be appropriate to the needs of some clients. Further research, involving interviews or observations, would be required to determine how well matched any of the reported interventions were to specific clients.

Various rationales were provided by respondents as underpinning the decisions SLTs make around the selection of different intervention. Rationales loosely followed the EBP framework but required further expansion of the traditional framework and inclusion of an additional component to a fully account for the data provided (See table 1).

Rationales mainly reflected the SLTs' consideration of client factors, particularly the benefits to the person with PMLD, rather than making specific reference to clinical experience or research evidence. It is heartening that SLTs report placing people with PMLD at the heart of the intervention decision making process, as this is more likely to result in more responsive interventions that map onto the lives of person with PMLD more readily. Areas of client-well being described included their wishes and preference being considered, their behavioural, communicative and emotional responses being observed and responded to, creating developmental opportunities to enable people to be able to act upon their environment and enrich their lives, and empowerment of people. For many of the interventions, however, more evidence is required to determine whether or not these benefits can be ascribed to the intervention. Such empirical evidence will serve to demonstrate different aspects of efficacy for the different interventions across a range of possible outcomes, including client and stakeholder wellbeing and possible developmental outcomes from different interventions.

It was, perhaps, surprising that families' and carers' views were not mentioned more extensively in the rationales. This appears at odds with the finding that 76% respondents

stated that they collaborated with carers. It may reflect the fact that carers are essential in implementation of communication interventions, but are rarely included in the decision making process, with their wishes or views seldom influencing SLT decision making. This would accord with findings in prior literature that family carers often felt they were not consulted by health professionals in decision making that affected their family members' lives (e.g. Goldbart & Caton, 2010; Chadwick et al., 2013). It may, however, simply reflect that respondents prioritised client factors in their reported rationales.

Prior knowledge, experience and expertise in working with this client group, and beliefs and expectations about particular intervention strategies were mentioned less than expected, particularly given Zipoli & Kennedy's (2005) findings that clinical experience and peer opinion have a stronger influence on decision making than the research evidence base.). One explanation is that such knowledge may be so integral to practice, and the need to deconstruct and report on it so rarely required, that these rationales are not actively acknowledged, butover-ridden by a focus on the more socially desirable well-being of the client . A further related explanation might coincide with that suggested by Phelvin (2012) in relation to learning disability nurses and Nind and Thomas (2005) regarding special education teachers. That is, that SLTs are using tacit theoretic and research knowledge which is so firmly embedded in their internal heuristic, that they regard matching the needs of individual clients against this internal model as "empowerment, development and behavioural preferences of the client" rather than regarding it as stemming from research evidence or theory. Clinical experience in this study, unlike Zipoli & Kennedy (2005) was not recognised as one of the most important

features of clinical decision making and warrants further exploration. the that has been in previous findings

Although there currently exists a relatively slim research evidence base for communication interventions for clients with PMLD, reported use of evidence fell short and did not accord fully with what was available; respondents rarely underpinned their rationales with research evidence in their responses. This was particularly apparent for the switch-based approaches where supportive evidence is available but reported use is very low, and for objects of reference where reported use is high but evidence is very limited. Only for Intensive Interaction (N=6) and training (N=1) was research evidence mentioned in the rationales given. This would corroborate McCurtin and Roddam's (2012) finding, cited above, that clinicians make only limited use of research evidence.

McCurtin and Roddam suggest that the lack of use of research evidence may be underpinned by a lack of support in terms of time and resources to engage with the evidence base. In their commentary on McCurtin and Roddam's paper, Erickson and Perry (2012) state that access to relevant research has been made far easier by online databases and abstracting services. This is incontrovertible, but access to the identified journal articles is often problematic for those working outside the university sector. Furthermore, whilst the switch-based interventions of Lancioni and colleagues are very well represented in resources such as SpeechBITE (http://www.speechbite.com/index.php), research on intensive interaction is limited to one (Zeedyk et al., 2009).

Selection of particular interventions reported by participants in the present study was influenced by organisational, practical and resource constraints. These factors formed an additional important factor alongside the tradition EBP components that are said to underpin decision making.

A tentative hypothesis from the data presented here is that although practice clearly varies across SLTs, therapists' rationales for using interventions for clients with PMLD appeared to be based primarily upon their perceived needs of clients (the primary stakeholders), with organisational factors and clinical expertise playing a role, with existing empirical evidence being less fundamental to decision making. Given the expectation in recent years for professions allied to medicine to engage in evidence based practice we expected therapists to provide far more evidence to support their clinical decision making. However, the relative dearth of published evaluations of interventions relevant to this client group, in addition to a somewhat partial abstracting of such research as there is, may in part account for our findings.

Limitations

Although this survey is the first to gather information about decision making and prevalence of communication intervention use, it is not without interpretive and methodological challenges that need consideration when drawing conclusions from the findings presented. Although the labels used in the survey for different types of

intervention followed the existing literature, they could have led to potential confusions and there may have been differences in the way that SLTs interpreted given terminology. The 'Other' category in the survey often contained interventions which were actually named earlier in the survey which may suggest overlooking or misinterpretation.

A further issue is that the survey may not have adequatelyelicited information on indirect, as opposed to direct, communication interventions. There is ambiguity as to whether staff training should be seen an indirect intervention in its own right, or whether the *content* of the training should be seen as the intervention. This distinction was not made explicit in the survey. Moreover, it seems likely that interventions were frequently not used in isolation. Future research could explore the combination of communication interventions for this client group.

We cannot find data on how many UK SLTs work with people with profound disability and hence cannot discern the representativeness of the sample or the response rate, though most qualifying programmes for SLTs in the UK were represented. The findings presented here are based on a self-selected opportunity sample of SLTs who are potentially more interested in this area and reflection on practice and decision making.

Employing a survey method lends itself to a breadth of description rather than a depth. Future research delving further into decision making processes regarding specific intervention types is indicated as this would further illuminate the clinical decision making process. A subsequent phase of this study is proposed to explore in depth the

evidence adduced for decisions regarding assessment and intervention approaches through individual semi-structured interviews.

Such description of the decision making process for each type of intervention with this client groups should also be accompanied by research exploring, first, the implementation of the different types of intervention across SLTs working with this client group. Second, the efficacy and effectiveness of the different types of intervention requires attention. Each intervention requires further evaluation using appropriate and rigorous methodologies to provide a robust evidence base in support of the 'best' interventions for particular subgroups of people with PMLD. For example, objects of reference, as one of the most often used interventions, needs further research both in relation to how it is operationalised and used with this client group and its effects on different clients.

Clinical implications

The explanatory typology outlined above retains and expands on the three main prongs of the EBP triad: client and carer views and values, clinical experience and research evidence. By adding Practical and Organisational Issues as a fourth element the typology reflects the pragmatic approach to clinical decision making often taken by SLTs when faced with the realities of limited time and resources. However, relatively few clinicians identified this as fundamental to their choice of intervention and the largest focus remains squarely in the area of client and carer views and values, with particular focus on the client's empowerment, development and behavioural preferences. This evidence

reinforces the client-centred work of most clinicians in practice, the effectiveness of which is borne out in the work of Bruce and Vargas (2007). They found that levels of intentional communication increased when people were involved in activities for which they showed a preference, that were familiar, and where an adult was close by.

There are, however, weaker areas that still need to be addressed. Clinical expertise as expressed above in terms of 'tacit knowledge' is partly what makes working with this client group successful. The ability to connect with people with PMLD on a one to one basis requires a level of empathy and observation that clinicians are often very good at (Phelvin, 2012).These skills are often interpreted by clinicians as 'expertise' and results from the survey clearly show that they consider themselves to have strengths in this area. Again, however, this expertise requires a robust body of research evidence to underpin it as effective intervention. An important starting point is to be aware of the current evidence available for specific interventions. However, there is much valuable research evidence that does not relate to specific interventions but that informs and shapes different interventions. Bunning et al., (2013), for example, look closely at the 'social interface' between adults and people with PMLD focusing on the quality and balance of interactions. Munde et al (2012) contribute research on influencing alertness levels in people with pmld. Integrating this information with empirical evidence on interventions and clinical expertise is essential in a field where the evidence base is still limited. Effective work with people with this client group involves expert attention to detail, skilled observation and the ability to maintain intervention 'fidelity' (Reynolds, 2013). These skills when implemented lead to gathering accurate data, replicating studies and

finally establishing the most effective interventions in practice. Speech and language therapists and researchers who work with people with PMLD are well placed to address the imbalance between expertise and evidence that are clear from these survey outcomes. The recent drive to form collaborative national HUBS (RCSLT) and the encouragement from the professional body to "move from anecdote to evidence" Simpson and Gadhok (2013) could be the catalyst that is required.

Conclusions

There is a mismatch between the approaches reported as used by SLTs with people with PMLD, and those evaluated in published research. The paucity of published evidence suggests a need for research to evaluate commonly used, but relatively unevaluated approaches such as Object of Reference, Communication Passports (which perhaps should not be seen as interventions) and even Intensive Interaction. There is also a need for in-service education to alert SLTs to the evidence base supporting certain approaches. The interventions described in this paper, whilst reflecting those for which *some* evidence exists, may not constitute all interventions used in practice, and hence for which evidence should be sought. The discussion has focussed around the trends for therapy intervention implemented by SLTs who filled in the survey.

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