

The role of Communication in Primary Healthcare for people with PIMD

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Background 1

- In the UK, strong evidence of avoidable and premature deaths of people with learning disability (e.g. CIPOLD report, 2013).
- People with PIMD have significant and complex health needs requiring more healthcare and more contact with healthcare services (Berg et al., 2007; Sone et al., 2008; van der Heide et al., 2009; Zijlstra & Vlaskamp, 2005)
- Health staff can feel unprepared to deal with the most pressing issues for family carers (Larson, 1998)
- Staff and services are not reliably making “reasonable adjustments” (Tuffrey-Wijne et al, 2014).

Background 2

- Family carers are the health advocates for many adults with PIMD but
 - find it hard to trust others with the care of their child & to be away from them (Twigg & Atkin, 1994);
 - feel disempowered in healthcare settings & can find getting along with health staff hard (Brett, 2002);
 - be tired from caring, feel they have little time from themselves & have little support (Chadwick et al., 2013; Families SIRG, n.d.).
- Family carers are skilled in the “complex and ambiguous” art of recognising pain (Findlay et al., 2015);

Background 3

- Increased need, diagnostic over-shadowing and limited adjustments make health care a difficult experience for families with a member with PIMD.
 - ✦ Is this also evident in other countries?
- Measures of family-centred **paediatric** care (MPoC, MPoC-SP) include items relating to Partnership, Respectful Care and Sensitivity.
- Bindels-de Heus et al., (2013) found that many parents find challenges in the transition from paediatric to adult health services – NL study.

Aim

To investigate parents' experience of health care for their adult children with PIMD.

Specifically:

- To explore how family members identify health issues in relation to their son/daughter with PIMD.
- To discern parents' views on the experiences of their adult children when receiving care from health services.
- To explore the impact of communication in healthcare settings on people & their family carers.
- To identify what caregivers believe would improve health services.

Method

- Phenomenological & transformative paradigms underpinned the research,
 - Valuing the views, experiences & understandings of family carers, exploring their lived experience.
 - Aiming to promote positive change.
- Hence, data analysis using Interpretive Phenomenological Analysis (IPA, Smith & Osborne, 2003).
- Participants: Purposive sample of 8 parents of adults with PIMD, living in the family home.

Data collection

- Interviews addressed parents' experiences of:
 - (i) Identifying health issues in their family member with PIMD;
 - (ii) Accessing & using health services with their family member with PIMD; and
 - (iii) Their views on how health services/care could be improved.
- Study conducted with speech & language therapists from the Manchester Learning Disability Partnership (MLDP), as funded capacity building project.

Participants

P	Carer: Relationship	Carer: Age band	Family Origins	Person with PIMD Age	Person with PIMD Gender
1	Mother	36-50	NW England	29	F
2	Mother	36-50	Northern Irish	31	F
3	Mother	36-50	South East Asian	26	F
4	Mother (Father present)	65+	NW England	45	M
5	Mother	36-50	Kenyan	25	F
6	Father	36-50	NW England	27	M
7	Mother	51-65	NW England	36	F
8	Mother	36-50	NW England	23	M

All interviews occurred in the family home. All interviewees were British citizens. Interview duration: 0:34:52 - 1:45:41; mean: 1:04:23.

Data Analysis

- Interviews were transcribed and uploaded into NVIVO.
- Descriptive and interpretive analyses were conducted.
- Ideographic accounts are being developed for each participant.
- Cross-case comparisons are being presented today.
- Quotes from the ideographic accounts are used for illustration.

Results

- Interview duration: 0:34:52: - 1:45:41; mean: 1:04:23.
 - Suggests this is an important area for interviewees.
- Five superordinate themes emerged:
 - Communication and History
 - Attitudes & Power in Healthcare
 - **Practical Healthcare Issues**
 - **Challenges in providing healthcare to people with PIMD**
 - **Impact on Parents & Person with PIMD**

Practical Healthcare Issues

1. Accessibility & Appropriateness of the Healthcare Environment
2. Variability & changes in healthcare
3. Liaising between health staff
4. Taking the appropriate time over healthcare
5. Expertise & skill of health professionals

Practical Healthcare Issues: Quotes

- I asked them to put the cot sides up when he came back from surgery; I must have asked half a dozen times. Yes, in a minute, Then when it got to about 1 in the morning he'd settled down and she said why don't you go home for a rest. So I said I will when you put cot sides up. So she said, oh, oh god we'd forgotten and well anyway they did come and do it.
- He couldn't swallow and he was all swollen here and he was obviously ill, and I took him and er he wouldn't open his mouth to the doctor to have a look down his throat. So he said well I can't do anything if he won't open his mouth. I said I beg your pardon, It's obvious he's got something wrong. He said he can't do anything. SO I got up and went to the desk and said could I make an appointment with another doctor which we did. He'd got tonsillitis.

Challenges in providing healthcare to people with PIMD

1. Identifying and diagnosing health issues in People with PIMD
2. Managing and treating health problems in people with PIMD
3. Presentation and variability in persons with PIMD
4. Physical aspects of healthcare for people with PIMD
5. Crisis, critical and emergency healthcare

Challenges in providing healthcare: Quotes

- She doesn't show signs; she had pneumonia, she didn't show signs of pneumonia; she had no temperature. It's weird but you know there's something not right.
- Every time you have an episode like that you add an extra couple of pieces to the jigsaw – understanding what you think things mean, so your knowledge builds up to the way he reacts to certain things through previous experiences. So you know you're probably a superb resource when you go to the GP because they know that you know.

Impact on Parents and Person with PIMD

1. Emotional impacts of healthcare
2. The caregiver role, burden and resilience
3. Carer attitude to healthcare & healthcare staff
4. Carer advocacy for adult child

Impact on Parents and Person with PIMD: Quotes

- Worthless! Is it me again? You start to believe it yourself. Am I being over-protective? I'm seeing things, and they make me feel very low and depressed. In the end I can't be bothered to pick up the phone and ask for help.
- I think with healthcare we've been quite lucky..... He has got a good GP, that is the basis for everything. Totally safe in their hands and she's going to look after him no matter.

Recommendations for Practice

Accessibility & Flexibility	Healthcare Professionalism	Healthcare Professional Disposition / Attitude	Carers' role
More physical space	Keeping up to date	Being caring & empathic	Showing perseverance
Reduced waiting times	Confidence in working with people with PIMD	Spending time and Taking time	Increase involvement in decision making
Identification of person with PIMD on arrival	Reliable response to phonecalls	Listening to & valuing parents' contribution	Preparation- the groundwork
More flexible/comfortable hospital facilities	Keeping information & discussions confidential	Giving reassurance & comfort	Highlight communication aids (e.g. traffic light etc.)
Home visits & Telephone consultation	Improve inter-professional liaison	Talk to person with PIMD & their carer	Have realistic expectations
Provide invasive procedures quickly	Pro-active working & Planning	Use communication aids (e.g. traffic light etc.)	

Conclusion and Discussion

- Some parents do experience good services in some settings, but there is great variability.
- Online training for GPs: <http://www.gmc-uk.org/learningdisabilities/default.aspx>
- Many problems are avoidable.
- Is family-centred care lost in the transition to adult services?
- Are these challenges familiar in other countries?
- How do we go about implementing the recommendations?

Key References

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