

SUPPORTING A PATIENT WITH INTELLECTUAL DISABILITY IN A GP CLINIC: A PRACTICAL APPROACH

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ABSTRACT

People with intellectual disability (PWID) pose a challenge to primary care physicians due to their complex care needs arising from their multiple biological, psychological, social, and family factors. Although the exact prevalence is not documented in Singapore, it is estimated that about 3 percent of the population has intellectual disability. The local primary healthcare landscape is due to undergo significant changes with the implementation of Healthier SG and this will see the enrolment of patients to one family physician to ensure ongoing care continuity and personalised healthcare for the local population. Primary healthcare providers are aptly placed to manage PWID, with the aim of maintaining these patients in the community and reducing the stressors that their secondary care partners are already facing. To achieve this, it is recommended that comprehensive assessments looking at the patient as well as their family, social, and care network be done. There are numerous obstacles to consider, from encouraging and allowing access to healthcare providers, to managing the consultation so that effective information exchange can occur to effective management of medical and behavioural issues and management of the patients' carer, family, and support network. An effective interprofessional approach in the management of PWID and support to their family/carers not only ensures their holistic well-being, but also their ability to integrate into the community.

Keywords: People with intellectual disability, practical approach, primary healthcare setting

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INTRODUCTION

The World Health Organisation (WHO) defines patients with intellectual disability as those who have “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence), which results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. This disability depends not only on a child’s health conditions or impairments but

also and crucially on the extent to which environmental factors support the child’s full participation and inclusion in society.”¹

PREVALENCE

The local prevalence of disability has been estimated to be about 3.2 percent among young children (birth to 6 years), 2.5 percent among school-going children (7 to 18 years), and 2.5 percent for those aged 18 years and above,² whilst Harris estimates the prevalence in the global population to be about 1-3 percent.³

Based on the above estimates, a full-time general practitioner (GP) in the UK who has about 2,300 patients registered under his/her regular care⁴ will have about 60-70 people with intellectual disability (PWID). The current primary care system in Singapore allows for a more mobile patient movement between primary care providers and there is currently no local data on the average numbers of patients registered per full-time GP in Singapore. However, if we were to assume an estimate of about 2,000 enrolled patients per full-time GP locally, we can assume an estimate of about 60 PWID under the regular care of each GP.

Studies have shown that PWID have a higher morbidity and mortality due to related chronic physical impairments, with the consequence of a 3-18 times reduced life expectancy when compared to that of the general population,⁵ with up to 45-50 percent of older PWID having undiagnosed hypertension, diabetes mellitus, and hyperlipidaemia.⁶ Therefore, based on such a high prevalence of chronic disease in this group, primary care physicians should be taking a more aggressive approach in performing health screening for PWID under their care.

However, healthcare provision for this group of patients poses a huge challenge for healthcare services globally. Barriers in preventing patients/carers accessing healthcare have been extensively studied and can be roughly classified into factors involving PWID, their carers, and the healthcare provider/service organisation.⁷⁻⁹

Recognised patient barriers include that of fear, stigmatisation, and embarrassment experienced by PWID and carers, which includes anxieties and fears relating to:

1. Blood tests
2. Vaccinations
3. Being judged over lifestyle choices¹⁰
4. Medical instruments¹¹
5. Fears that arise from a lack of understanding about screening procedures¹²
6. Physical examinations potentially being a source of embarrassment and/or discomfort for individuals with intellectual disabilities^{13,14}

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Other barriers that fuel anxieties in PWID relate to the clinical environment, commonly involving unpleasant or alarming noises¹⁵ and excessively bright lighting,¹¹ as well as a lack of understanding of why patients are in the waiting room, and not properly mentally preparing the patient by explaining the reasons for needing to visit the clinic on that occasion.¹⁶

Therefore, mental preparation from families of/carers to PWID regarding impending visits to the healthcare provider along with adjustments in the clinical environment, such as easy-read information, coloured pictures, models, photos, videos, symbols, and demonstration dolls, would help allay such anxieties in PWID, making further future visits a less stressful experience for service users.^{17,18}

A cross-sectional survey of Singapore healthcare providers by Sajith et al in 2017 revealed the following:

1. 90 percent of respondents identified the lack of communication skills in persons with ID as affecting the medical assessment;
2. 66 percent of healthcare providers felt that the lack of sufficient knowledge about the mental and physical needs of PWID affected their ability to provide proper care; and
3. 75 percent of respondents felt that they needed further training so that they could provide proper care for PWID.¹⁹

This article will look at the four main identified areas of potential challenges in literature faced by healthcare providers to PWID in trying to ensure proper facilitation of care:

- A. Appropriate adjustments within the clinic environment and workflow²⁰
- B. Confidence in managing behaviours of concern demonstrated by PWID
- C. Ensuring accuracy of information exchange among patients, carers, and members of the healthcare team. This reduces misdiagnosis and ineffective communication¹⁸ and involves:
 1. Direct and patient-centred communication with patients
 2. Indirect communication and ensuring accurate translation of information provided by carers/families and support workers
 3. Clarifying and then utilising the patients/carers language and lingo
 4. Addressing the perceptions and health beliefs/concerns and understanding of PWID and that of their carers²¹

- D. The need to improve primary prevention, and management of presenting issues using the biopsychosocial approach, whilst working in partnership with the PWID, their carer/families, and support network

CLINIC ENVIRONMENT AND WORKFLOW

The following are suggestions to reduce the fear and anxiety associated with visiting the healthcare provider:

Role of the Primary Healthcare Team

Rapport, trust, familiarity, and relationship building, as well as cementing understanding of the PWID and their carers together with the doctor's management style, is best achieved by continuity of care with the same healthcare provider and team.

Making clinic staff within the clinic aware of such an appointment serves to:

- A. increase staff awareness of patients' appointments to allow them to identify patients when they arrive.
- B. provide a more personal service to patients and carers.
- C. address patients by their first name/preference when they arrive.
- D. ensure as smooth of a registration process as possible.
- E. monitor patients in the waiting room for any discomfort and anxiety and make the clinician aware if this happens so that appropriate measures can take place, such as:
 - i. seeing patients as soon as possible.
 - ii. getting patients to wait in the second empty adjoining clinical room.
- F. prioritise dispensing/billing and administrative matters.

Appropriate Appointment Length

This is usually needed because PWID have a tendency towards more complex biopsychosocial needs, and therefore more time needs to be provided during each healthcare encounter. Adequate time is a major factor in ensuring proper communication as well as ensuring rapport and relationship building. Late morning appointments or the last appointment of the clinical session are usually preferred to achieve this.

Lighting

Natural and non-fluorescent light in the premises have been shown to help accommodate patients with issues of sensory integration.^{22,23}

Size of Examination Room

Larger rooms, where possible, help to facilitate adaptive equipment, wheelchairs, and allow carers and other healthcare workers (where necessary) to accompany the

patient to the consult. This will help with making the patient feel more secure and comfortable.

Appointments Scheduling

Scheduled appointments, where planned, serve to reduce waiting time in the clinic.²⁴ Where regular appointments are needed, fixed same day and timed appointments (e.g., every week or month) are helpful as it helps facilitate a routine for these patients, and to ensure easier schedule planning for busy carers.

BEHAVIOURS OF CONCERN

Emerson²⁵ defines behaviours of concern (BOC) as “culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities”. The impact of BOC on PWID, their caregivers, and family can be significant and should never be forgotten when encountering PWID. Recognised behaviours include aggression, agitation, stereotypical and self-injurious behaviours, as well as behaviours directed towards inanimate objects.²⁶ Due to inconsistencies in definitions and study methodologies, the challenges that clinicians face in differentiating between BOC, and atypical behaviours of mental health disorders, the exact prevalence is unknown with ranges from studies lying between 5.7 to 17 percent.²⁷⁻³⁰ Diagnosis of BOC is further complicated by the fact that between 14-30 percent of PWID are taking psychotropic medications even though a diagnosis of a psychiatric disorder is not present.^{31,32}

The following are suggestions when dealing with behaviours of concern:

1. Perform a thorough and comprehensive assessment to ascertain the possible causes by obtaining a thorough history from family, carers, and various members of the healthcare team – formal and informal alike. The impact of BOC on PWID, their caregivers, and family can be significant and should never be forgotten when encountering PWID.
2. Ensure the creation of an “enabling environment”,³³ which is essential in supporting patients with BOC rather than purely focussing on antipsychotic medications, especially in the absence of a robust diagnosis of a psychiatric disorder. This is best achieved by working with the other interprofessionals in the team and caregivers to identify and then rectify any issues with the support network as well as environmental circumstances.³³ Where needed, specialist assessments (behavioural therapist, psychologist, or psychiatrist) should be arranged.³⁴ Therefore look for the following:³³
 - i. Any changes to social or home situation,
 - ii. Stressful environments

- iii. Understimulating or overstimulating environments – noisy or restrictive environments
 - iv. Lack of privacy
 - v. Lack of coadaptations, which cater for other coexisting disabilities.
3. Assess for medical/physical health issues that might be contributing to the BOC, e.g., pain, adverse side effects of medications and current acute illness.³⁵
 4. Conduct regular reviews of medications to identify the rationale and use of the psychotropic medications and the need to continue with these medications, as well as looking out for adverse effects.^{36,37} Studies recommend psychotropic medications as a last resort for managing BOC, only once other causes have been excluded and only for as short a term as possible.³⁸
 5. Any life experiences that might be distressing towards the patient will also need to be screened for.^{39,40}
 6. Psychiatric conditions, e.g., mood-related illnesses, anxiety, and adjustments disorders are then considered once the above have been attended to.⁴¹ Where needed, a referral to a mental health team for further assessment has been shown to be helpful in dealing with BOC.

EFFECTIVE CONSULTING AND COMMUNICATION

Effective information exchange from all parties involved is crucial in communicating concerns, expectations, symptoms, and more importantly the effect that this is having on the PWID, their carers/families, and support network. Three main issues will be looked at next:

3. The relationship between time and effective consulting
4. Consulting effectively during each encounter
5. Issues surrounding decision making capacity

THE RELATIONSHIP BETWEEN TIME AND EFFECTIVE CONSULTING

Time and effective communication are closely intertwined and play an intricate relationship in achieving successful consulting outcomes with all patients. Studies and surveys looking into the role of both time and communication in healthcare provision for PWID have consistently shown time to be a major barrier – from prolonged waiting times to see the doctor to that of limited time spent with the healthcare professional during the appointment.¹⁶ Prolonged waiting times, even in a familiar environment, has been shown to be a major cause of anxiety and stress for PWID.^{43,44}

Sufficient time facilitates effective exchange of information and ideas between PWID and their carers,^{45,46} safeguards

both patients and the clinician in arriving at the incorrect diagnosis and ensures that appropriate agreed management can be instituted.⁴⁷

Therefore, appropriate time allocated provides opportunities to establish rapport and to build a relationship with PWID and their carers and ultimately encourages further accessibility to healthcare services, overcoming any negative perceptible barriers that can potentially exist.⁴⁸

Despite recognising the importance of spending time getting to know the service user, some healthcare providers unfortunately still struggle to find extra time to achieve this familiarisation.²⁵

Suggestions to achieve this include:

1. Allocating and planning double consultation time to give PWID the opportunity to formulate questions, as well as to give themselves more room so they will not feel hurried during busy practice hours.⁴⁹ This will allow the exchange of information among the clinician, PWID as well as their carer/support worker.
2. Scheduling appointments in advance, where possible, to the portion of the clinical session where there is less anticipated human traffic and fewer patients, i.e., avoiding potentially busy days (e.g., Mondays), as well as timings in the day, i.e., towards the end of the clinic session whereby there is less of a rush to have to work through patients waiting to be seen. Therefore, early morning appointments are avoided as much as possible, and staff would generally encourage late morning appointments or appointments around midday whereby the patient volume usually tends to be lower.
3. If the patient turns up in the middle of a busy clinic session, utilise any empty clinical/administrative rooms present or adjacent to the consulting room, where available and needed, for the comfort and privacy of the PWID and their carer so that they can wait in a more comfortable and secluded area whilst waiting to be seen.
4. Physical examination should both be explained and demonstrated before examining the patient to allay any anxiety before examining the patient.⁵⁰
5. The rules of triadic communication (i.e., communication between healthcare provider, carer and PWID, allowing equal contributions and considerations of all parties involved) should be followed. This also facilitates the opportunity, where appropriate and with consent of the carer/support worker, for the clinician to demonstrate the physical examination on the carer/support worker (non-touch examination where possible) or on a dummy or the clinician himself.

Effective Consulting

In Smith et al's⁵¹ national survey, PWID noted problems communicating with clinicians significantly more often

than persons without disability. This was most likely due to failures of physicians to listen to patients' preferences or in engaging them sufficiently in decision-making. Patients find engaging healthcare stressful mainly due to poor communication between all parties and this leads to these patients lowering their expectations from such encounters and a gradual disengagement.⁵² This leads to poorer psychological and physical outcomes and the consequent social and mental stressors on carers and families.

The Australian Management Guidelines on Developmental Disability highlights that: "[...] people with developmental disability appreciate doctors who: talk to them respectfully, do not shout, explain what is happening, treat them as if they are worthwhile, listen to what they are trying to say, say when they do not understand them, allow enough time for the consultation."⁵³

Carers also contribute to dysfunctional communication, most commonly by not allowing the service user to speak for themselves or by behaving in a manner so as to protect the PWID from perceived harmful communication.⁵⁴ This therefore prevents PWID from exerting control over their own healthcare needs, creating a feeling of further loss of autonomy, resulting in effective information exchange. Loss of autonomy also affects self-confidence and is associated with an increase in anxiety because the PWID does not feel that they have been listened to. This potentially could tempt the healthcare provider to communicate directly with either carer/family or support worker and not the PWID directly.^{17,55} Studies have shown that this lack of communication knowledge and understanding amongst healthcare providers leads to the development of negative attitudes such as disengagement, coldness, and abrupt communication towards PWID.^{25,56} Such attitudes have also been shown to exist in non-healthcare professionals across both primary and acute healthcare provider settings.⁵⁶

Suggestions to try to facilitate comfortable exchange of information between all parties involve providing a patient-centred approach to PWID. This has been shown to positively affect their overall wellbeing and health⁵⁷ and assumes that the PWID is central to all that occurs around him, from communication to deciding and planning care. As discussed, additional time and an individual approach is needed. This generally involves:

1. Demonstrating a warm, personable, friendly, and caring attitude to encourage and allow service users to easily access healthcare facilities and discuss sensitive health concerns.⁵⁸⁻⁶⁰
2. Addressing patients directly and exploring their preferred methods of communication with various preferred communication tools explored early in the clinical encounter. Verbal and non-verbal cues should be looked out for.
3. The freedom for patients to express their own perceptions of their problems and in a manner comfortable to them.

In his clinical practice, Hollins tends to have a pen and paper ready on hand for himself and his patients to facilitate this.⁶¹

4. Continuity of care (as mentioned above) is important as it provides opportunities to gain a better understanding of the communication styles of the PWID, thereby facilitating medical history-taking, and the eventual communication of the management plans. This leads to a more personalised healthcare service for these users.
5. Treating PWID with dignity and respect,⁴⁵ which is valued by PWID. Therefore, clinicians should always introduce themselves to the PWID at the outset of the consultation, followed by their carers/support workers, as well as to always seek their thoughts/perceptions and opinions regarding proposed management.⁶² PWID find it challenging making valid decisions if they are unsure of who is questioning or informing them.⁶²
6. Identifying at the outset someone who knows the patient well, and who will be able to support the PWID, as well as helping coordinate their appointments and care, and ensuring all involved are aware of the health concerns, needs, and perspectives of the PWID.⁶³
7. Discussing and facilitating for all parties involved the goals of care as well as the values and considerations that help guide this decision-making process.⁶⁴
8. Where appropriate, slowing the speed of information exchange down to ensure that all parties understand and take in what has been communicated, with specific attention to issues of health concerns from PWID and carers.⁶⁵
9. Care being taken to ensure that the healthcare provider does not take over or overly influence the decision-making process.⁴⁹
10. Spending time alone with the PWID, where appropriate, to provide the opportunity to communicate any issues over safety or health concerns.⁶⁶

Issues Surrounding Decision-Making

Perry et al⁶⁷ made the interesting observation that while PWID are generally allowed to make choices about issues involving their everyday lives, decisions related to the health of the PWID were made by their carers, families, and healthcare providers and not the patient themselves. This is in contradiction to what PWID have expressed in interviews – they wanted treatment on the basis of equality and wanted to make their own decisions and to have free choices.⁶⁸ Therefore when checking understanding, it is helpful to invite the patients to convey back in their own words as to what has been explained. This helps in seeing if the patient has understood and retained the important information that has been communicated rather than asking a closed question of whether the PWID has understood what has been said or not.

Healthcare providers should take into consideration, where possible, that the involvement in the decision-making process for PWID is an essential part of their healthcare and should be something that healthcare practitioners encourage.^{58,69} PWID feel empowered when they are involved in the decision-making process and gain a better understanding of their treatment and diagnosis, and thus will be encouraged to take ownership for their health.^{54,70} It is also well evidenced that PWID value healthcare professionals, their support network, and other professionals who together with their specialist knowledge and experience work closely with them.⁷¹⁻⁷⁶

Therefore, it is worth considering the following in the decision-making process:

1. Whether the PWID understands what the problem facing them is and what would happen if nothing was done.
2. Whether their caregivers, family, and support workers understand the decision that needs to be made and the implications of the various options presented.
3. Adapt the communication to the patient where appropriate and involve all parties who are familiar with the patient.⁷⁵
4. Ensure a shared decision-making process with PWID and their caregivers.⁷⁷
5. Propose consulting another trusted family member or caregiver in the event that the legal substitute decision maker does not know the patient well.⁷⁷
6. Screen for factors that might affect the decision-making ability of PWID, e.g., intercurrent illness or recent events that might have affected them psychologically or changes in social circumstances (illness or separation from someone close to them).⁷⁸
7. Collaborative interagency approaches in more complex issues have been shown to alleviate the service user's healthcare fears,⁷⁹ as well as helping to provide a more personalised tailored service that is person-centred, flexible, and family-centred. Such approaches are highly regarded as a necessity in the care of PWID as well as their carers and families.^{42,80-84}

BIOPSYCHOSOCIAL MANAGEMENT OF PWID

The biopsychosocial model of care is generally advocated when considering management in PWID.

Pharmacological Considerations

PWID have been known to have a higher risk of chronic disease and any prescription needs to take into consideration the issues surrounding polypharmacy and long-term use of certain medications.⁸⁴ Studies have also shown that PWID tend to suffer more considerable adverse drug reactions

and effects that end up impacting their quality of life negatively.⁸⁵⁻⁸⁷ As a consequence of this, there are campaigns such as STOMP-LD (Stopping Over Medication of People with Learning Disabilities, Autism or Both) in the UK that aims to address inappropriate use of psychotropic medications.⁸⁸

Suggestions to take note of when prescribing include:

- A. Creating time to regularly review (e.g., every three months) the date of initiation, indications, dose, effectiveness, and adverse drug reactions or unwanted effects of all medications.⁸⁹ This should also include time provided for patient and carers to discuss any questions about their medications.^{90,91} Studies have shown that pharmacist reviews are a very effective means of dealing with this in primary healthcare settings when such resources exist.⁹⁰
- B. Educating patients and caregivers about medications, including⁹²:
 - i. Appropriate use of medications
 - ii. Potential interactions of medications with over-the-counter medications
 - iii. Other alternatives to medications prescribed
 - iv. Appropriate use of as-needed medications
 - v. How to recognise and then report potential adverse drug events
- C. It is good practice to consider the following when making the decision in prescribing medications⁹³:
 - i. Determining the patient's capacity for both decision-making and medication compliance
 - ii. Simplifying the medication administration routines
 - iii. Recommending appropriate medication administration aids (e.g., dosette boxes, blister packs) where appropriate

Primary and Preventative Medicine

Studies have shown that preventative care and disease detection play an important role in managing the health of PWID, and various health assessments that address the specific health issues of people are strongly recommended.⁹⁴ Studies advocate the following:

- A. Periodic comprehensive health assessments with adaptations to aid with physical and mental health assessments, along with a review of the social (home and community) support have shown to be beneficial in identifying needs⁶²
- B. Healthcare plans can then be created based on the identified needs and prioritised based on acceptability to patients and caregivers.⁹⁵ It is helpful to provide the patient and their carers with such plans. A properly

formulated healthcare plan is recommended in many guidelines and helps to serve the following⁶⁶:

- i. Facilitation of partnerships and engagement from patients, carers, and the interprofessional health team
- ii. Helps with specific goal-setting
- iii. Clarifies the responsibilities of all involved in the care of the PWID

Psychosocial Issues

PWID more commonly experience abuse, exploitation, and neglect when compared with the general population. This can be in the form of verbal, physical, emotional, sexual, and financial exploitation.⁹⁶

PWID experiencing abuse can present in the following ways:

1. Unexplained changes in physical health (e.g., malnutrition)⁹⁶
2. Unexplained changes in mental health (e.g., anxiety and depression)
3. Changes in behaviour (e.g., withdrawal, disruptive behaviours, and inappropriate attachments)
4. Patterns of inadequate care – missed appointments, non-engagement, and non-adherence

Therefore, where opportunity arises, it is recommended to sensitively assess for risk factors such as the residential setup and home support, as well as to look for possible indicators of abuse, exploitation, and neglect.⁹⁷ If abuse and exploitation is suspected, the relevant authorities will need to be informed, with referral to the local services for assessment.⁹⁸

Regarding families, carers, and support workers, studies have shown and confirm that they commonly experience considerable physical, mental, and economic stress, and that they are often overlooked by healthcare providers when caring for PWID.⁹⁹ An increase and changes in life events will further add to their stress, and where possible, respite should be encouraged. Weiss and Lunsky advocate using tools like the Brief Family Distress Scale to screen for carer stress¹⁰⁰ Proactive approaches to support the identified needs of carers, which include respite, regular monitoring of mental wellbeing, and interventions to increase carer coping strategies and skills, have been shown to be effective.⁹⁹⁻¹⁰²

CONCLUSION

The primary healthcare landscape in Singapore is due to undergo significant change with Healthier SG on the horizon and could place more strain on the already limited resources in primary care. Primary healthcare providers are viewed as problem solvers and manage a huge variety of cases, using a biopsychosocial approach for their patients, with the aim of

maintaining these patients in the community and reducing the stressors that their secondary care partners are already facing. As clinicians, it is our duty of care to look after all the patients who are enrolled in our clinics, and this includes PWID.

PWID post a challenge to primary care physicians due to the complex care provision required for them, which arises from the multiple biological, psychological, social, and family factors that exist. To achieve this, an interprofessional approach in the management of PWID to ensure holistic well-being, and the ability to be able to integrate into the community, with support to patients and family/carers has to be considered.

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