

FAMILY EXPERIENCES OF PSYCHIATRIC SERVICES FOR THEIR RELATIVE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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AIMS

- Explore the research and guidance around family experiences of psychiatric services for relatives of those with intellectual and developmental disabilities
- Review some of the common challenges and key difficulties
- Discuss ways to manage or mitigate these issues

INTRODUCTION

- When a relative develops a mental or behavioural issue that requires the support of services, it can be highly distressing for their families and carers.
- If that relative also suffers from an intellectual or developmental disability (IDD), this can be even more difficult
- This is due to problems accessing services adapted to their loved one's needs.

- There is strong recognition of the important role that families can play in patients' recovery.
- Many people with intellectual disability have small social networks and therefore their family members are intensely important to them.
- Contact with and support from families is often a key factor in sustaining a patient's motivation and sense of self-worth
- Recent NICE guidelines recommend that professionals work in partnership with family carers

KING'S FUND REPORT

- Foot et al noted that involving families and carer's is an essential part of good patient care.
- Their diverse roles include:
 - providing emotional, social, and financial support
 - domestic assistance
 - monitoring health and wellbeing
 - providing basic health and personal care
 - helping to provide professionals with information about the individual
 - advocating for individuals
 - proactively seeking out care and treatment options.

POSITIVE OUTCOMES

- Meaningful involvement of families is associated with positive outcomes for patients, carers and service quality.
- Patient outcomes include increased knowledge, confidence, and understanding of their health problems, reduced rates of relapse and admissions to hospital.
- Involvement can enhance self-confidence, and provide carers with the opportunity to learn new skills.
- Organizational benefits include improved staff confidence and teamwork, and reduced numbers of complaints.
- The 'triangle of care' concept - a holistic approach that brings together carers, patients, and health professionals, and which aims to promote safety and recovery for people with mental health issues by including and supporting carers.
- Foot et al. (3) outline that the involvement of families and carers should be considered at all stages of care-planning, decision-making, and delivery, with the same thought and attention as for the patient.

FAMILY EXPERIENCES

- Unfortunately, families often report that their experiences do not reflect this guidance,
- They have had to ‘fight’ to access services
- Once they have accessed care, their liaison with professionals and services has been challenging
- An experience that is very often described in other healthcare settings too.
- Important to consider barriers to family involvement and review development of some good practice standards, in order for clinicians and services to begin establishing and nurturing positive relationships with patients’ families.

CHALLENGES

- Research has typically framed the experiences of families with a relative with DID negatively, in terms of stress and burden
- Some families report lower levels of psychological wellbeing, self-esteem, and chronic levels of stress.
- Family carers report experiencing a lack of acceptance, negative attitudes, feeling blamed for their relatives behaviour, and being stared at in public, therefore restricting their activities; and thus loneliness, isolation, stigma, and reduced quality of life
- Emotional issues such as grief, loss, causation, guilt, and worry about who will look after their relative when they pass away are common.

REDRESSING THE BALANCE

- Overemphasizing stress and burden creates an overly negative perception of having a relative with DID.
- Further research has attempted to redress this balance, and provide a more balanced perspective,
- Many families talk about their child with DID in exactly the same terms as their children without DID, as a source of joy and happiness
- Families have reported expanded personal and social networks and community involvement, an increased sense of purpose, personal growth and strength, strengthening of family unity and closeness, increased tolerance and understanding.

REDRESSING THE BALANCE

- It is important to recognize that all families are different.
- Children and adults with DID have highly heterogeneous levels of disability and associated needs and behaviours.
- Accordingly, their relatives have varying degrees of coping skills, and levels of personal support.
- Caring evolves through several transition periods of stability and change— starting and leaving school, adolescence and leaving home, with differing degrees of challenges and predictability.

MENTAL HEALTH PROBLEMS

- People with DID are equally, or more likely, than the general population to experience mental health problems
- Lives can alter immeasurably when a close relative develops mental health difficulties
- The illness can mean the person experiences personality changes, becomes unpredictable, and in a minority of cases, violent.
- Families can suffer financially, due to being unable to work due to their caring commitments.
- However, people with DID often face additional difficulties in obtaining mental health treatment.

MENTAL HEALTH PROBLEMS

- These difficulties include problems establishing a reliable psychiatric diagnosis, due to receptive and expressive language deficits that limit the ability of an individual to articulate their internal experience and emotions.
- Some people with DID actively attempt to hide their symptoms, to appear competent.
- People with DID find it difficult to navigate through services and to negotiate the care they need.
- Mental disorders among people with a DID often present in atypical ways and coexist more frequently with autism, epilepsy, and other neurological disorders.
- Diagnostic overshadowing is another issue, where psychopathology is attributed to the DID, and the potential for comorbid mental illness overlooked.
- This is important, as diagnosis is often key to accessing services, and providing a basis for treatment.
- Family members are heavily relied upon to provide a pivotal advocacy role in alerting professionals to changes in their relatives presentation

EXCLUSION CRITERIA

- A further barrier to mental health treatment for people with DID can be ongoing disagreements about whether care is provided by generic/ mainstream, or specialist services.
- There is wide international variation in provision, with the UK and The Netherlands having the most developed specialist services. In Scandinavia, the USA, Australia, and most of Western Europe, care is mainly provided by general psychiatric wards or services
- This is relevant due to the impact on patients and their families. Care may suffer because of boundary disputes between specialist and general services—with possible exclusion from both
- Families have reported difficulties accessing support, getting the GP to refer them to a specialist, and then facing long waiting lists
- Parents have described services often as fragmented, uncompromising, hard to reach, and not in accordance with their needs
- Carers frequently report ‘fighting’ to obtain services, noting that situations need to reach crisis point before help is provided

INPATIENT ADMISSION

- Research exploring the carer perspectives on their relative's admission to in-patient settings highlighted that this can be a disempowering experience, especially if unplanned, due to professionals assuming the role of experts and having control over decisions and care of their relative.
- Carers can become uncertain regarding the definition of their role and how they fit into the care being provided
- While their relative is now being cared for outside the family home, families may remain in a crisis state due to the uncertainty and continuing concern (particularly about their child's vulnerability and that they will not be cared for in the same way that their family would).
- A further difficulty is the 'language of mental health'.
- Families have described concerns around transitions, and lacking coordination of care when an individual is ready for discharge into the community from inpatient services, with increased uncertainty and anxiety about reduced levels of support for their relative
- This is not because staff do not care, rather that they inevitably become occupied by tasks, demands, and focus on the patient.

TREATMENT OF PATIENTS WITH PSYCHOSIS

- In a systematic review investigating family involvement in the treatment of patients with psychosis, Eassom et al. highlighted the systemic reasons for poor involvement of families.
- Staff overwhelmingly reported on the practical aspects of family work: that it requires time, resources, and funding and is difficult to integrate with other clinical casework, particularly in areas with high demands and clinical crises.
- Specific needs reported for family work included flexible hours and the accommodation of family requirements such as childcare facilities or home visits.
- These issues were compounded by reports of services and managers not making time allowances for family work (e.g. work out of hours, funding for training)
- Financial cuts impact on quality of care across all aspects of service provision, including family involvement.
- Cultures in which family involvement is not promoted are not conducive to quality care. (e.g. the public inquiry into the care failings and substandard care at Mid Staffordshire NHS Foundation Trust noted that a significant factor within the events which occurred was that relatives felt excluded from effective participation in the patients' care)

IMPROVING FAMILY EXPERIENCES

- A developing body of research has sought to understand what families expect from services caring for their relative.
- There are a number of issues which carers commonly raise as unsatisfactory in relation to their interactions with professionals and services.
- Families want to have adequate access to services that listen to their concerns, and they are also keen to have a diagnosis that explains their relative's current difficulties and informs the treatment plan that is proposed.

ISSUES – AND HOW TO ADDRESS THEM

- **Capacity assessments and ascertaining patient's wishes regarding family involvement** - Prior to initiating contact or sharing information with an adult patient's family, a capacity assessment should be undertaken.
(Note this can be a contentious issue – one we'll explore later)

ISSUES – AND HOW TO ADDRESS THEM

- **Proactive and meaningful inclusion and involvement -**
Consider and treat your patient's relative as a member of the team, or colleague. Recognize and respect their expertise and knowledge on their relative's history, current presentation, past and present response to treatment, and what is likely to work in regards to future plans.
 - **Good quality, inclusive information -** Provide carers with information on:
 - The signs and symptoms of mental ill health
 - the current and developing needs of their relative
 - how to manage their relative's condition
 - their relative's rights whilst within services
 - available services and financial support
- (Both prior to accessing the service and during care)

ISSUES – AND HOW TO ADDRESS THEM

- **Accessibility:** a) **Of services** - Services should be ‘joined up’ and easily accessible to patients and carers. Access procedures should be reviewed from the point of view of families.
- **b) Of clinicians.** - When meeting and communicating with families, be friendly and approachable. Outline your contact preferences and availability. Consider providing a ‘key worker’.
- **c) Of procedures.** - Explain the background to procedures and processes to help understanding. Provide carers with information on what to expect following an assessment or meeting
- **d) Of language.** - All information provided to families, whether written or verbal, should be inclusive and accessible. Provide full explanations of acronyms and complex terms,

ISSUES – AND HOW TO ADDRESS THEM

- **Diagnostic overshadowing.** - Do not assume any issue arising is due to the DID. The reason for seeking treatment will usually be due to a change or deterioration in presentation which has been observed by those around the patient. Undertake a full mental health assessment, seeking support from a DID specialist, if available.
- **Develop the knowledge.** - Take the time to review any information which has been provided prior to consultations. When time is scarce in a busy clinic, patients would prefer to be kept waiting an extra five minutes while you read the referral letter or scan the case file. Write detailed notes about your consultations with patients in order to share your developing knowledge with the team, and review others notes and reports.

ISSUES – AND HOW TO ADDRESS THEM

- **Listening** - Remember that families know their relative the best and are the most familiar with their history and behaviours over many years. As such they are often well placed to report on any changes in health or behaviour. Acknowledge and listen to families views and manage any disagreements professionally, highlighting the reasons for your opinion or decision in a transparent manner.
- **Welcoming environment** - Review the environment from the point of view of a family member. Do they create a good first impression? The environment should be made welcoming and accommodating of visitors

ISSUES – AND HOW TO ADDRESS THEM

- **Support for carers** - Consider providing a support group/online network for carers. Signpost to relevant local/national services or groups. Be supportive and respectful at all times.
- **Auditing carer experience and satisfaction** - Family and carer experience should be measured routinely as part of the annual audit cycle, and any positive or negative comments and suggestions considered and acted upon, as necessary.

STANDARDS FOR ACHIEVING MEANINGFUL FAMILY INVOLVEMENT

- Foot et al. set out some broad standards outlining how to achieve meaningful family involvement in health services:
 - Organizations should have a carer policy that is well communicated to staff, with training programmes and specific remits for staff around involving carers.
 - Health professionals need to identify carers, and then keep this information up to date in medical records.
 - Involving carers requires the agreement of the individual who they are caring for.
 - Subject to consent, information should be shared with the carer, including details of services, diagnosis, treatment options, and support mechanisms.
 - Carers should be involved in care-planning and discharge plans from hospital, as team members.
 - Carers should receive adequate support with their own needs. This can range from arranging appointments at times of the day when carers can get cover, through to providing formal periods of respite care. In the UK, the Care Act 2014 mandates that carers have the legal right to an assessment and support from their local authority.

STANDARDS FOR ACHIEVING MEANINGFUL FAMILY INVOLVEMENT

- Within these standards, some important areas to consider.
- When identifying carers, it may be that the patient's closest familial bond is not with parents, but a grandparent, sibling, or cousin, or for those who have grown up in local-authority/state care, a foster carer.
- Some patients do not have a carer. (Cheshire, Chester, Graham, Grace, and Alexander reported that approximately 20 per cent of patients detained within in-patient specialist forensic DID services were not in contact with their families)
- This highlights the need for an individualized approach, and to develop knowledge and understanding of each individual patient's family context.

ISSUES AROUND CONSENT

- It is important to obtain consent from the patient as to whether they wish for their family to be involved in their care, and specify what this contact will look like.
- This is a decision which requires an assessment of the patient's capacity
- If the patient is assessed as lacking capacity then any action taken, or any decision made on behalf of that person, must be made in their 'best interests'.
- This process may involve an IMCA
- A further consideration at this stage is to assess whether any safeguarding issues are present.

ISSUES AROUND CONSENT

- People with DID are vulnerable to abuse, because of dependence on other people for personal care; ‘imbalances of power’ between the carer and the person being cared for; communication difficulties; lack of sexual knowledge and assertiveness; and guilt and shame at being disabled.
- Research has suggested that many people with DID in in-patient services experience painful relationships with family, and histories of conflict and abuse.
- Alexander et al. reported that as many as 50 per cent of patients within forensic DID settings have experienced abuse. Furthermore, this abuse may be the reason services are required, with victims of sexual abuse having higher rates of mental illness, behavioural disturbance, and post traumatic stress disorder, with the severity of the effects related to the severity of abuse.
- If abuse is uncovered, or disclosed by the patient, safeguarding processes are activated to protect against further abuse.

STANDARDS FOR ACHIEVING MEANINGFUL FAMILY INVOLVEMENT

- This process can be frustrating for family members, with the perception that confidentiality is used by professionals as a way to not share information.
- However, patients emphasize how important the opportunity to consent is to them, strongly linked to self-esteem, privacy, personal choice, independence, autonomy, general wellbeing, and empowerment
- The only situation in which information should not be shared with family, is if a patient with capacity, has requested it be kept private, or if the capacity assessment has deemed family contact is not in the patient's best interests.
- This situation is very difficult for relatives, particularly if a relative is withholding contact and information.
- There are a number of reasons why patients may not wish their relative(s) to be involved in their care: privacy concerns (keeping the extent of the illness from the family), fears of placing relatives in a position of power, or of exposing their vulnerability.
- The rationale for withholding any information should therefore be explained in a transparent manner to relatives.
- It is important to outline that consent will be reviewed regularly, and so the situation may change in the future.

INFORMATION SHARING

- Once consent has been obtained and the patient's wishes ascertained, the process of information sharing and involvement can begin.
- A useful starting point is if the main professionals involved introduce themselves to their patient's relatives, describe their role in the team, their practice remit in relation to policy, legislation, accountability, professional codes, organizational boundaries and resource availability.
- There is no prescriptive guidance as to the frequency, or modes of contact, as this will depend on the individual situation of the carer and their other commitments, among other factors, and may also evolve over time.
- It is important for agreed contact times and methods to be adhered to, and to make contact at the next opportunity, if something comes up which affects whether an agreed telephone call can be made.

INFORMATION SHARING

- While information is provided from the care team to the carer(s), such as revisions to the working diagnosis and care plan, discussions around visits, meetings, and progress, a lesser discussed role of the family is the value of the information they provide on their relative, which is crucial to numerous aspects of assessment and treatment, such as;
 - the 'getting to know you' process,
 - developing a diagnosis,
 - and to assess levels of risk.
- Ideally, a patient's family are contacted at an early stage of the patient's contact with services.
- Family members are often pleased to supply a full account of the patient's life, which is hugely valuable, providing a full picture of their life and who they are, their behaviour across contexts, and key events and timeline.

NICE GUIDANCE

- NICE emphasise the importance of professionals, services, and family carers working in partnerships for involvement to be meaningful.
- Consideration needs to be given as to how families are involved, so that they do not feel sidelined, powerless or overwhelmed, but fundamental to the care process.
- Some carers have reported being invited to particular sections of meetings, and gaining the impression that decisions have been made prior to their attendance.
- Good communication processes, such as information sharing and joint working between professionals, agencies, and relatives are also important.
- This could include, regular multiagency care reviews, joint strategy meetings, and a shared list of all agencies/professionals involved with an individual and their family.
- Providing validation about their knowledge, positive feedback, and treating carers as members of the care team, supports the development of positive relationships.
- Identifying a key worker, who acts as a single point of access to a service and professionals can ensure carers are empowered and kept involved by co-ordinating meetings, assessments and contact

DISAGREEMENTS

- On occasions, there may be disagreements on diagnostic, management, and treatment decisions between relatives and others within the team.
- This may be because carers and professionals recognize and understand the needs of the individual differently based on their relationship, knowledge, and experience.
- Conversely, relatives can experience denial about the extent of their relative's difficulties.
- Carers may be concerned about the use of medication or other treatments they perceive as restrictive and potentially harmful
- As a consequence, conflict may occur and professionals need to manage this disagreement and try to find a pragmatic resolution which benefits the patient.

GROUPS FOR FAMILY MEMBERS

- A developing area of practice is in the provision and evaluation of groups for family members.
- Chiocchi and colleagues described a carer-led programme for mental health carers co-delivered over 20 two-hour training sessions. Sessions included mental health psychoeducation, family skills, and problem-solving sessions.
- There was a high number of referrals to the programme, and an evaluation indicated improved well-being, reduced burden, and increased family empowerment in carers.

GROUPS FOR FAMILY MEMBERS

- Smallwood et al. described a caregiver support service, which offered individual and group psychoeducation, practical advice, and emotional support, working alongside usual community mental health provision for people with established psychosis.
- The evaluation suggested improvements in wellbeing, and in caregiving experiences.
- Rye et al. described a group for young people with a sibling having a disability, which aimed to increase understanding about disability, provide a space for peer support and skills development, for self care, and care of their siblings.

CONCLUSION

- Families go through a lot to support their relative, forgoing their own needs, and experience significant stresses and traumatic experiences to do so.
- It is therefore imperative that professionals working in services do their utmost to support this group, alongside providing quality care for their relative.
- There are a number of common themes consistently raised by the families of those with DID accessing services.
- While it must be acknowledged that services are generally more likely to receive criticism than praise, there are a number of recommendations which can be adopted by all services which can support the provision of good quality care across the lifetime of people with DID.

CONCLUSION

- One recommendation relates to the prevention of development and worsening of mental health and behavioural problems in people with DID, via the provision of good quality information to those caring.
- This information needs to be provided sensitively, and in a timely manner, so as not to frighten families about all the potential negative outcomes facing their child, whilst giving an indicator of what signs to look for so that help can be obtained.
- Relatedly, the need for the right diagnosis at the right time, has implications for services.

CONCLUSION

- Following the aftermath of the Winterbourne View abuse scandal in the UK, some have questioned the need for specialism, and indeed psychiatry in the care of people with DID.
- While a mainstream model of care may be preferable to some, it is clear that the diagnosis of mental health problems in this population requires a degree of specialist expertise, preferably from an expert in the mental health of people with DID or alternatively from staff who have had equivalent training.
- It is this professional expertise that guarantees an equity of treatment outcome for a vulnerable patient group.

CONCLUSION

- The recommendation of a key worker, or a named point of contact is one that many families would value.
- One only needs to reflect on a personal dissatisfaction with being unable to access the same GP or specialist doctor to recognize this basic need to develop a relationship with a professional with ongoing understanding and knowledge of your, or your relative's case history and current treatment.
- On the other hand, this should be managed in a flexible way, so that one professional does not 'own' the relationship with a particular relative, and therefore the relative receives no contact when that staff member goes on holiday or sick leave.

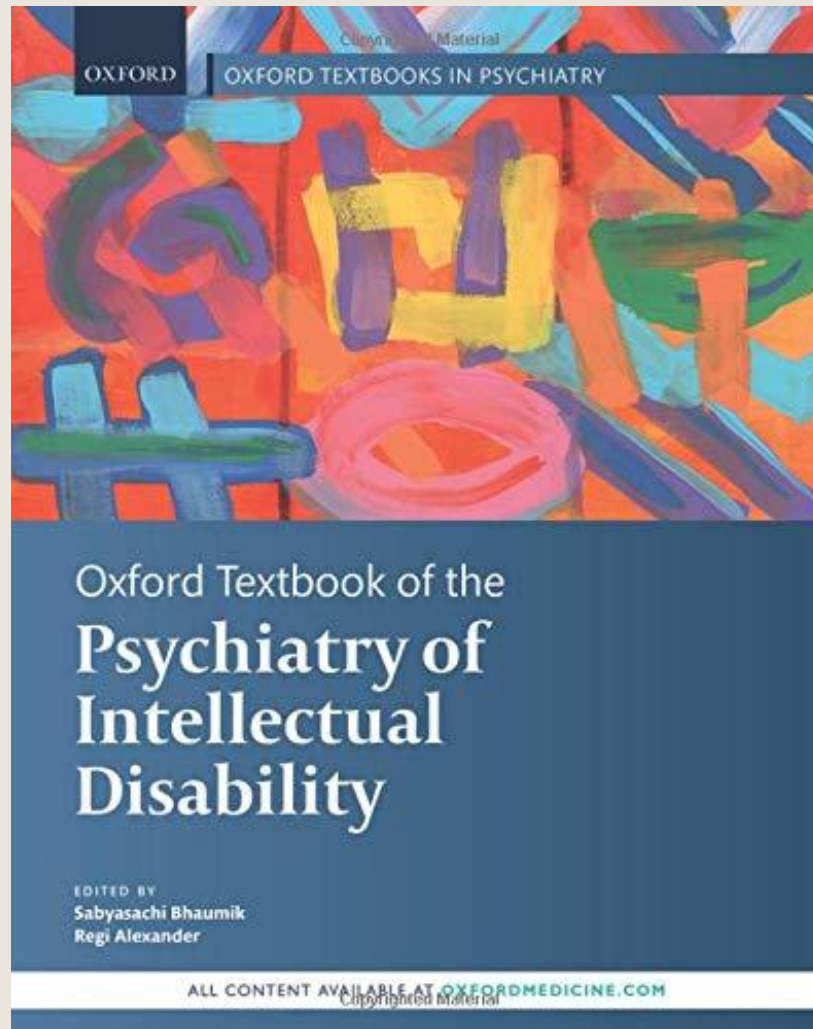
CONCLUSION

- The need for carers to be listened to, is a recurrent theme which crops up in most family narratives.
- If the starting point is honest, and collaborative relationships between families and services, this should not be a problem.
- However, staff working within services can be known to take the line 'we know best'.
- In some cases, the service will know best, and in others, the family will, and in the majority, the truth will lie somewhere in between.
- Sometimes the only way to ascertain the best diagnosis or approach is for one party to try to listen to the other's suggestion and vice versa.
- It is important that a respectful culture is fostered so that any disagreements can be managed positively.
- If these recommendations are practised, it is likely that positive relationships can be developed between services and patient's relatives and carers, improving outcomes for all parties.

CONCLUSION

- Undoubtedly, there is currently a lack of social and professional support for families of relatives accessing services.
- While generic carer services are of some utility for practical information and support, newly developed specific services which are linked to the service their relative is receiving have been rated positively by families.
- These services are in their infancy and will only succeed if substantially funded by governments.

FURTHER READING



QUESTIONS AND COMMENTS