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Keeping families in mind

GEMS

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Gateway to Evidence that Matters

Ulysses agreements in supporting families affected by parental mental illness

Quick Facts

- Ulysses Agreements can be defined as a plan collaboratively developed by a family and relevant mental health professionals whereby decisions are made regarding the care of children, for when the parent becomes unwell as result of their illness.
- The name Ulysses Agreement comes from the story of the Greek, Ulysses, who ordered the crew of his ship to lash him to its mast and disregard what he had to say, if he told them to steer the ship towards the rocky shore where voices were beckoning him. Like Ulysses, parents with mental illness, whose functioning may be compromised at some point, can be encouraged to plan ahead for times when they are less well and so less able to 'steer' their families.
- Families need to feel empowered and at the centre of their Ulysses Agreement Ulysses Agreements are formulated around the family's unique strengths and needs.
- Ulysses Agreements can range from simple verbal agreements to carefully crafted documents that can be shared with others.

This GEMS will present research regarding Ulysses Agreements (sometimes referred to as Advance Care Plans, Care Plans, Crisis Plans or Advanced Directives) defined as a plan collaboratively developed by a family and relevant mental health professionals¹, whereby decisions are made regarding the care of children, for when the parent becomes unwell as a result of their illness². Research has shown that 21-23% of children live in homes where at least one parent has a mental illness³. Furthermore, children who have an affectively ill parent have a 40% chance of experiencing an episode of depression by the age of 20, which increases to 60% by the age of 25⁴, thus necessitating the need for early intervention.

Parental mental illness is a complex and multifaceted problem, requiring a collaborative and integrated service delivery to meet the needs of parents, family members and children⁵. However, there is a paucity of research on specific collaborative practices that focus on families affected by a parent's mental illness. Of specific interest, are Ulysses Agreements, which, while they may differ within regions and countries, usually include the purpose of the plan, symptoms of the illness, unique family strengths, issues of communication and confidentiality, a wellness plan of action, children's needs, and conditions for cancellation and evaluation^{1,6,7}. They are often used to minimise the potential negative impact of a parent's hospitalisation and the disruption of family relationships by providing a reliable, predictable course of action that is known by all individuals involved.

Two publications on Ulysses Agreements exist in the areas of eating disorders⁸ and addictions treatment⁹. In Australia, 28 parents and children, where the parent had a mental illness, suggested

that Crisis Plans should be called 'Care Plans' and focus on planning for potential crises as well as caring for all family members¹⁰. The only other research on families affected by parental mental illness was a qualitative, explorative study in British Columbia, Canada, which involved interviews with five parents, five professionals and one family member¹¹. This study utilised the Critical Incident Technique^{12,13}, asking participants what helped or hindered their experience of developing a Ulysses Agreement, as outlined below.

Helping factors

The factors that facilitate this process include parents who:

- had increased self-awareness of their mental illness
- were motivated to care for their children
- had a general sense of motivation to get well.

Professional factors that facilitate this process include those who:

- provided moral support and educational information
- were personally invested and motivated
- were accessible for contact and clear about their roles and limitations
- built rapport and trust with the parent and family members.

The Agreement was also strengthened by other factors such as:

- the involvement of extended family and friends
- having a written and tangible document
- the emphasis on prevention and early intervention.

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Hindering factors

Parents were less able to prepare Ulysses Agreements when they:

- struggled with symptoms of mental illness
- lacked trust and rapport with professionals or family
- lacked support from family and/or friends
- denied or lacked insight into their illness
- experienced social stigma from family or professionals about their illness.

Professional characteristics that hindered the development of Ulysses Agreements included:

- a lack of information sharing between professionals
- a lack of rapport with parent and family
- a lack of time and resources.

Other hindering factors included incidents where:

- family and friends were unable or unwilling to participate
- there were challenges updating the agreement or logistics of meetings
- family and/or friends also struggled with mental health or substance use issues.

Limitations

There is clearly a lack of research on the implementation and impact of Ulysses Agreements for families affected by parental mental illness. We are still unclear as to how children should be involved in these Agreements and at what ages. Additional research on the efficacy of Ulysses Agreements, across a broader population of parents with mental illness and their children is warranted. Research on the experiences of dependent and adult children¹⁴, about their experiences of developing and subsequently implementing Ulysses Agreements would be useful.

Clinical Implications

When developing Ulysses Agreements with families where a parent has a mental illness, it is important to be strength-based and to facilitate empowerment for the parent, children and other family members. Establishing trust and safety with the family is crucial prior to developing an effective plan, as is the involvement of extended family and friends. Additionally, there is a need for the clinical training of professionals in the broad area of parental mental illness and more specifically in regards to developing successful Ulysses Agreements.