Title: My child’s future mental health: carer’s engagement with risk identification in an intervention study for youth with At-Risk Mental States

Running title: Carer’s engagement with risk identification

Authors: Michael Tham 1,2, Sarah Bendall 1,3, Thomas Carlyon-Stewart 1,2, Andrea Polari 1,4, Jessica Hartmann 1,3, Melissa Kerr 1,3, Paul Amminger 1,3, Patrick McGorry 1,3, Barnaby Nelson 1,3, Aswin Ratheesh 1,3

Institutions:

1. Orygen Parkville, Australia
2. Melbourne Medical School, University of Melbourne
3. Centre for Youth Mental Health, University of Melbourne
4. Orygen Specialist Programs, Parkville, Australia

Corresponding author details:

Aswin Ratheesh
35 Poplar road, Parkville, VIC

Word Count: 2961

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/eip.13206

This article is protected by copyright. All rights reserved.
Abstract

Aim: Prevention and early intervention efforts of serious mental illnesses has yielded promising results. However, alongside benefits, several ethical concerns have been raised, including the effects of being identified as being at-risk. In these debates, the voice of parents or carers is conspicuously absent. This is especially concerning as several at-risk interventions are trialled in under-age youth where parents consent on behalf of young people. Therefore, this study aimed to understand carer’s experiences of their teenager being identified as at risk for psychosis.

Methods: Semi-structured interviews were conducted with seven carers who had provided consent for their teenager to participate in a stepped intervention study for youth at-risk for psychosis. Questions explored their experiences regarding having their teenager being identified as at-risk. Transcripts were analysed using thematic analysis.

Results: We identified five main themes from seven female carers’ experiences of risk identification including: (a) recall of risk information was limited, or variable, (b) goal of risk disclosure was perceived to be positive, (c) negative emotions were associated with knowledge of risk, (d) relief from uncertainty and helplessness and (e) effects of risk disclosure were mediated by individual circumstance.

Conclusion: Overall, the results demonstrate that carers’ experience of risk disclosure varied with factors surrounding their individual circumstances, and the process of disclosure. Whilst participants acknowledged potential adverse effects associated with risk disclosure, many still adopted a positive outlook. Tailoring safe and effective disclosure of risk to suit the needs of youth and carers could outweigh the potential risks.

Key words: identification, carers, psychosis, prevention, risk
Introduction

A key strategy to reduce the impact of major mental illnesses such as psychosis is to focus on prevention. Identifying those at-risk of developing a mental illness is an integral component of this strategy, which germinated as the ‘Ultra-High Risk (UHR) approach (Yung et al., 1996). UHR classifies individuals as at-risk of developing psychosis based on the presence of significant family history, sub-threshold positive psychotic symptoms, and decreased functioning (Yung, McGorry, et al., 2007; Yung et al., 1996). While the majority of people who meet the UHR criteria will not go on to develop a psychotic disorder, their risk is considerably higher than that of the general population. Significant strides have been made in refining this process of classification as well as improving the validity of risk prediction models (Hartmann et al., 2018). However, accompanying these advances have been the recognition of several ethical issues regarding the effects of risk identification, particularly in the field of psychosis prevention (Corcoran et al., 2005; Malhi et al., 2020; McGorry et al., 2001). Recognised concerns include stigma – especially when individuals identify themselves with risk labels (Yang et al., 2019), distress, and exposure to potentially harmful treatment side-effects (Mittal et al., 2015). Furthermore, the risks may be iatrogenic given the strong possibility of false identification as well (Yung, Yuen, et al., 2007). On the other hand, some authors suggest there is also risk in withholding information on diagnosis (Corcoran, 2016), and highlight the need for care in the pre-psychotic stages (Woods et al., 2020).

The balance between the benefits and risks of risk identification across serious mental illness has been summarised and discussed across multiple review articles (Macdonald et al., 2017; Mittal et al., 2015; Nelson et al., 2017; Ratheesh et al., 2017). However, there are comparatively few studies exploring patient and carer perspectives and experience surrounding preventive interventions (Loughlin et al., 2020).

Further clarification of these perspectives has the potential to directly align future interventions and research with patient and carer needs. Of the studies specifically exploring consumer experiences of
psychiatric risk identification, four pertain to young people at-risk of psychosis, including their experiences of risk identification (Uttinger et al., 2018; Welsh & Brown, 2013), their attitude towards at-risk labelling terms (Kim et al., 2017), parental stigma (Baron et al., 2018) and their perspectives regarding genetic counselling (Lawrence et al., 2016). Overall, these studies revealed that young people may not experience stigma directly as a result of risk identification. In fact, risk identification may provide benefits such as relief via an explanation of their symptoms.

To date, no study has explored the experiences of risk identification in parents of teenagers at symptomatic risk of serious mental illness including psychosis. Parents, as legal guardians, play an influential role in determining the care their young people receive, as well as defining their family environment, the nature of which has been shown to moderate the functioning of those at high psychosis risk (Thompson et al., 2019). Additionally, parents may share markedly different preferences regarding risk identification compared to their teenager’s, especially with respect to the means of identification. In one study, parents with bipolar disorder were also more likely to prefer specialised interventions, while at-risk youth preferred access to non-clinical peer support (Davison & Scott, 2018). Such differences indicate that there is a need for further research in this area.

This current study aims to explore the experiences of risk identification among carers of young people with at-risk mental states for psychosis. A broader group of carers were selected to ensure inclusion of non-parental guardians. Our objective was to uncover insights into how they react to and process risk identification which will in turn inform future clinical-research endeavours in at-risk states for psychoses, and other mental disorders.

Methods

We conducted a qualitative semi-structured interview study using thematic analysis methodology with approvals from the local Human Research Ethics Committee [MH HREC 2015.173].
Participants
This study was conducted alongside a large, multi-step intervention study called the Staged Treatment in Early Psychosis (STEP) study (Nelson et al., 2018). STEP implements step-wise interventions to young people meeting UHR criteria. The study recruited participants from Headspace settings. Headspaces are non-specialised youth mental health centres that provides support to young people aged 12-25 years, focussing on early intervention.

Selection criteria:
We aimed to recruit 6-12 parents (Malterud et al., 2016), carers or legal guardians of teenagers aged 12 to 18 years who had already consented to STEP. Carers of STEP participants were chosen as they were in the unique position of having had their teenagers’ risk of future mental illness already disclosed to them through the STEP study consent process. As the consent form specified the risk for psychosis, we anticipated that the process of consent would acknowledge the nature of risk, and the implications of how this risk may change within the interventions in the study. Further requirements for participation included ability to provide written informed consent, English proficiency, and an identified general practitioner to ensure support would be available in the event of participant distress.

Procedures
Recruitment and consent process: Research assistants (RA) identified and gained assent and parental contact details from teenagers involved in STEP. The investigator then contacted carers by phone and invited them to the study site to provide full informed consent and complete the questionnaires and interview.

Semi-structured interview:
The interview format was semi-structured, involving a set of open-ended questions exploring parental experience as well as perspectives developed by two of the senior investigators (SB and AR). Interview questions were based on the ethical framework proposed by Beauchamp and Childress (2001). The
interview schedule was organised in order to introduce the different interview topics in steps, clarify the
carers’ experiences of risk disclosure, and ensure that questions were clear and simple. Considering the
sensitive nature of the subject material, the schedule was devised in a stepwise fashion, beginning with
more general questions to allow the participant time to get comfortable before moving onto the risk-
related questions. The interview began with general questions about the carer as well as their teenager’s
presentation to Headspace. Subsequently, carers were asked about their understanding of the magnitude
of their teenager’s risk of developing future mental illness, in particular psychosis, bipolar disorder and
major depression. If a teenager’s risk was identified as high by the carer, they were then asked about their
experience of becoming aware of that risk.

Investigator MT conducted all interviews. Participants were scheduled interviews lasting 60-90 minutes
that were taped, transcribed and conducted between March and June 2019. After informed consent, pre-
interview questionnaire of basic participant information was firstly filled out, followed by a series of
questions regarding the teenager’s problems. This was followed by the main interview after which the
participants were briefly screened for any potential distress caused by the interview, and offered
counselling via available onsite psychiatrists as well as a follow-up phone call 2-4 weeks post-interview
to discuss any concerns.

Analysis

Data analysis was carried out using thematic analysis (Braun & Clarke, 2006). Thematic analysis is a
widely used approach for identifying, examining, and reporting patterns within a data set (Braun &
Clarke, 2006). It involves immersing oneself in the data and systematically abstracting meaning from the
initial transcript. This is done by firstly by translating participant responses into codes which represent the
most basic element of information that can be used to meaningfully assess a phenomenon. Subsequently,
codes are processed into themes which are observed patterns within the data set that communicate in
broader terms its significance. This study employed an inductive approach to interpretation. By doing so however it is important to acknowledge the researcher’s own lens of interpretation. The current study utilised a framework of ethics outlined by Beauchamp and Childress (2001) and an understanding of the current literature in prevention of mental health illness to contextualise emerging themes throughout the analytical phase.

Results

Overview of participants

In total, 19 teenagers assented to the interview and provided carers’ phone numbers. Only one carer was selected per teenager. Seven of the carers consented to and completed the interview, six were uncontactable after multiple attempts, one declined, and five were unable to complete the interview within the assessment period. The main reasons given for being unable to complete the interview were difficulties in commuting to the interview site and incompatible participant schedules.

The following themes were identified from codes relating to carers’ experience of risk identification.

1. Recall of risk information was limited, or variable

Carers differed in their recall of having their teenager’s risk disclosed to them whilst being consented for STEP. Three carers had no recollection of being given risk information [P1, P3-4].

“Oh I can’t remember. This was a while ago now (2 years), but they probably would have.” [P4]

However, all carers were aware of their teen’s risk of future mental disorders when asked about this directly. Out of the four carers who fully remembered risk disclosure, half only remembered the phrasing of the risk disclosure in general terms [P2, P7]. For the other two carers, mentioning of specific illnesses such as “bipolar” was recalled. Two carers [P5, P7] recalled the wording as “being a good candidate” for the research study.
2. Goal of risk disclosure was perceived to be positive

Carers felt that risk disclosure was not blaming and not associated with negative intent.

“I didn’t feel attacked, I didn’t feel like my daughter was going to be put in a box and be labelled.” [P5]

Secondly, carers perceived disclosure as actionable information, in that it motivated them to take action to support their teenager.

“All I was thinking was like, I’ve got to be there to support him and (if) things go wrong, I’m there.” [P6]

3. Negative emotions associated with knowledge of risk

Being identified as at-risk elicited a range of negative emotions. The most prominent one was worry which was mentioned by five of the carers. Out of these five, three of them experienced worry directly from the risk disclosure at the time of consent [P2-6]. The other two described worry arising from thinking about their teenager being at risk more generally [P4-5].

“I was worried, you know. Like what’s going to happen in the future? Like is it going to get better, or is it going to get worse?” [P2]

The memory of being preoccupied with her daughter’s risk caused some distress for one carer during the interview [P5]. One of the sources of distress was related to the carer considering that the teenager could feel somehow flawed [P1-2].

“You don’t want your child to have something wrong with them and to feel bad, because it makes them feel horrible” [P1].

Carers also worried about fears of stigma and isolation as a result of risk disclosure.

“I just didn’t want my kid, my daughter to be picked on because she’s got her own issues going on and kids they just say just stupid sh*t sometimes.” [P5]

Some carers articulated a sense of hopelessness from the suggestion that their teenager may develop an ongoing serious mental illness.

“It’s like telling someone you’re more likely to develop cancer... is there anything you can do?” [P7]

Finally, carers also recalled feelings of guilt.
“At first it made me feel guilty because my past history and my family’s past history has a lot of depression... I thought “Oh have I done something wrong? Was it me? I’ve got the genes.” ” [P6]

4. Relief from uncertainty and helplessness

Four carers described a feeling of relief from having their teenager’s risk being identified [P2-3, P5-6]. Much of this relief arose from knowing that it meant their teenager would receive support through STEP.

“Relieved. Well relieved that there’s something out there to help these kids. In my day, there was nothing.” [P4]

For some, relief appeared to be imparted through the explanation that the risk information provided [P2, P5]. This explanation allowed one carer to redirect the meaning and responsibility of mental illness from her teenager.

“Kinda yeah releases the burden I think when you can say well it’s not so much your fault.” [P2]

The carer later revealed the “burden” referred to both her teenager’s and her own.

5. Lived and familial circumstance mediated the effects of risk identification

Carers perceived the effect of risk identification on themselves and their teenager as dependent on several individual factors. The most salient factor was familiarity with mental illness, particularly from having a family history of mental illness [P5, P7]. One carer had an extensive family history of schizophrenia, growing up with the constant fear of developing it. For her, further risk information had little impact.

“It was just what it was, do you know what I mean?...It wasn’t scary talking to him about it” [P7].

Contrastingly, risk disclosure in one carer with both direct familial links and lived experience exacerbated her worry for her two teenagers both currently involved with STEP.

“We kind of already knew that (she) would be at-risk given her mother's illness... ” [P2]

Contextual information available was another moderating factor in processing risk information.
“If it's not backed up by any education, or it's not backed up by anything else, it's quite frightening...”

[P2].

Discussion

In our qualitative examination of carers’ experiences and perspectives regarding teenagers being at risk, we identified experiences relating to both challenges and benefits of risk identification. Moreover, the carers’ experience of processing risk information was highly variable and depended on the context of risk disclosure, as well as individual differences and circumstances.

A number of carers had trouble recalling risk disclosure, which either suggests that to some, the act of identification may not be salient, or alternatively that the process of identification may not have emphasised the risk itself or labels related to risk. It is possible that in the clinical trial, the risk was not discussed after the initial consent, and thus the implications of increased risk may not have registered among carers. It is possible that the researchers themselves may have been acting on their potential concerns of stigma related to risk terminology, (Kim et al. (2017), and its downstream effects such as internalisation of stigma, shame, and discrimination from others (Corcoran, 2016).

Despite some inconsistencies recalling initial risk identification, carers overall viewed risk disclosure as a positive act, whilst acknowledging the potential to evoke negative emotions such as worry for their teenager’s future. This could have been a product of receiving risk information in context of having their teenager participate in an intervention study; gaining access to year-long professional support may have overridden initial feelings of apprehension. One explanation could be that carers were more worried about finding support for their teenager’s increased risk, than the increased risk alone.
The more familiar and informed carers were about the nature of their risk and symptoms, the more relieved and less fearful they were towards them. This finding is consistent with two studies in which negative attitudes towards a clinical vignette of an individual at risk of psychosis were diminished when given more relevant and specific information about it (Parrish et al., 2018; Yang et al., 2013), as well as in a study where teenagers with at-risk mental states described relief from having an explanation for their current symptoms via risk disclosure. However, intimate familiarity may be detrimental, as one study identified higher stigma in patients with a family history of psychosis (Kim et al., 2017). This suggests that the context of the information is important in determining a given reaction.

Individual and situational differences also explained other more negative reactions, particularly among family members who experienced guilt regarding genetic transmission of mental disorders to teenagers. Parents with bipolar disorder in another study expressed feelings of guilt from the idea of passing down their risk genetically (Davison & Scott, 2018). Attributing illness course to genetics (Austin & Honer, 2005) or environment (Selkirk et al., 2009) can both generate these underlying feelings. Consultations with a trained counsellor that reinforces the notion that no single factor caused such illnesses has the potential to alleviate some of the guilt and self-blame (Ryan et al., 2015).

**Limitations**

The main limitations for this study include issues with sample selection, risk disclosure practices in STEP, and the timing of the interviews. Regarding the sample, all carers recruited were unintentionally female. A possible explanation for this may include the normed gender roles associated with female careers in facilitating appointments or care at Headspace. Secondly, risk identification in STEP may have occurred without a strong emphasis on future risk using clear labels. This limits the comparability of our results to other research who do use risk related labels, or from qualitative literature in genetic counselling where clearer risk terms are used.
Implications

Carer responses appear to advocate for a holistic and personalised approach to disclosing risk. Macdonald and colleagues (2017) provide one such holistic framework that conceptualises decision-making for ethical risk disclosure as an algorithm of patient factors. A pre-disclosure questionnaire that integrates these factors into an accessible decision-making tool would help clinicians tailor risk disclosure to suit their patients’ needs. The use of individualised risk calculators may help inform risk disclosure in a more nuanced fashion (Fusar-Poli et al., 2018), although these need further refinement for use in clinical populations. Synthesising the views of both carers and their teenager at risk could provide insight into developing strategies for disclosure that balance both of their concerns.

In all, carers experience of risk identification was complex, nuanced and context-dependent; whilst risk information carried some saddening implications, its meaning could still be construed in a helpful and constructive manner. By furthering our understanding of the beliefs and experiences of carers within this domain, additional steps can be made in providing safe, effective, and tailored preventative services to those who would benefit from them the most.
Acknowledgements

The authors acknowledge the contribution of families and teenagers who participated as well as the research assistants in the STEP study who facilitated the current sub-study.

Declaration of Conflict of Interest

The authors have no conflicts to declare in relation to the current manuscript.

Data availability statement

The data are not publicly available due to privacy or ethical restrictions.
References


https://doi.org/10.1111/eip.12459


https://doi.org/https://doi.org/10.1016/j.atg.2015.06.001


Table 1

*Participants’ demographic information*

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Participant Age</th>
<th>Relationship to teenager</th>
<th>Child age</th>
<th>Child gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>42</td>
<td>Mother</td>
<td>15</td>
<td>F</td>
</tr>
<tr>
<td>P2</td>
<td>40</td>
<td>Aunt</td>
<td>15</td>
<td>F</td>
</tr>
<tr>
<td>P3</td>
<td>47</td>
<td>Mother</td>
<td>17</td>
<td>F</td>
</tr>
<tr>
<td>P4</td>
<td>54</td>
<td>Mother</td>
<td>12</td>
<td>M</td>
</tr>
<tr>
<td>P5</td>
<td>40</td>
<td>Mother</td>
<td>16</td>
<td>F</td>
</tr>
<tr>
<td>P6</td>
<td>48</td>
<td>Mother</td>
<td>18</td>
<td>M</td>
</tr>
<tr>
<td>P7</td>
<td>40</td>
<td>Mother</td>
<td>15</td>
<td>M</td>
</tr>
</tbody>
</table>
Tham Michael (Orcid ID: 0000-0002-3215-6371)

Polari Andrea (Orcid ID: 0000-0002-0680-3192)
Author/s:
Tham, M; Bendall, S; Carlyon-Stewart, T; Polari, A; Hartmann, J; Kerr, M; Amminger, P; McGorry, P; Nelson, B; Ratheesh, A

Title:
My child's future mental health: Carer’s engagement with risk identification in an intervention study for youth with at-risk mental states

Date:
2021-08-19

Citation:

Persistent Link:
http://hdl.handle.net/11343/298861