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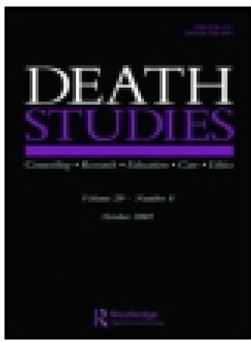

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Help-seeking experiences of bereaved adolescents: A qualitative study

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ABSTRACT

Despite the potentially devastating effects of a death on the lives of adolescents, little is known about their help-seeking experiences. We interviewed by telephone 39 bereaved adolescents on their help-seeking experiences. Thematic analysis resulted in three themes: *Formal support*, *Informal support* and *School-related support*. Participants provided a critical appraisal of positive and negative experiences, and noted barriers and facilitators for help-seeking. As

adolescents bereaved through suicide may receive less social support, professional help is a much-needed auxiliary. Parental encouragement is important in accessing adequate professional help.

KEYWORDS

Adolescent; bereavement; death; help-seeking; social support; suicide

Experiencing a death during adolescence is associated with adverse physical, mental and social outcomes (Balk, 2014). The death of a family member signifies the loss of a primary caregiver, whereas the death of a friend implies the loss of an intimate at a time when identification with peers is more important than that with parents (Balk, 2014). Adolescence is a susceptible stage of life for the onset of mental disorders. About one in four to five adolescents experience a mental health condition (Kessler et al., 2012), and 75% of adult mental disorders occurs before the age of 18 in New-Zealand (Kim-Cohen et al., 2003) and 25 in the US (Kessler et al., 2012), emphasizing the importance of early detection and treatment (McGorry, Purcell, Goldstone, & Amminger, 2011). However, only 18 to 34% of adolescents with depression or anxiety seek professional help (Gulliver, Griffiths, & Christensen, 2010).

The level of psychological distress, in particular high levels of depression, predicts whether an adolescent seeks professional help (Rickwood & Braithwaite, 1994). In a large population study, the majority of bereaved adolescents (87%) never or only sometimes talk about the death of their relative or friend, most do not feel a need for professional help, and those most depressed are most likely to talk with a professional (Harrison & Harrington, 2001). Yet, the literature highlights the importance of the relational and mental health context of adolescent bereavement and suicide bereavement alike (Andriessen, Draper, Dudley, & Mitchell, 2016; Balk, 2014). Further, although the course and duration of grief after suicide seem similar to other types of bereavement, some

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characteristics, such as feelings of guilt, shame, stigma or rejection, may be more pronounced, and render suicide bereavement more challenging for the mental health of vulnerable adolescents (Andriessen, Dudley, Draper, & Mitchell, 2017). Adolescents who are bereaved by suicide are at increased risk of new psychiatric problems, mostly depression and anxiety, shortly after the death and irrespective of the kinship relationship with the deceased (Andriessen et al., 2016). In addition, suicide-bereaved adolescents are at increased risk of suicidal behavior, especially after parental suicide, independent of family history of psychopathology (Mittendorfer-Rutz, Rasmussen, & Wasserman, 2008).

Social support is associated with positive grief outcomes; yet, bereaved adolescents experience insufficient social support through limited support providers and/or duration of the support (Ringler & Hayden, 2000). Similarly, suicide bereaved adolescents may experience insufficient social support. The few qualitative studies in this field (Bartik, Maple, Edwards, & Kiernan, 2013; Hoffmann, Myburgh, & Poggenpoel, 2010; Silvén Hagström, 2013), noted a change in dynamics of relationships with bereaved adolescents narrowing their circle of close relationships. The bereaved adolescents experienced a reciprocal lack of understanding within their social environment, and relationships became more troubled or avoidant, which hindered their help-seeking.

In general, 15% to 76% of suicide bereaved people receive no professional help (Wilson & Marshall, 2010). However, studies have rarely explored the experiences of suicide bereaved adolescents. A study of sibling suicide noted that only 6% of siblings received help for more than 3 months, and 45% missed help from psychologists (Dyregrov & Dyregrov, 2005). Hence, 65% of parents reported a need for more and longer-term help for bereaved siblings after the suicide of one of their children. Similarly, the majority (69%) of suicide bereaved young people indicated a

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need for professional help (Dyregrov, 2009). They reported a lack of energy or motivation, especially in the absence of parental recognition of the need for, or encouragement to seek professional help, as a major barrier to receive help. As such it is possible that those adolescents most in need of help may face the most difficulties in getting it.

It is crucial to understand the help-seeking experiences of bereaved adolescents, a group at risk for ill-mental health and suicidal behaviour. However, studies to-date are limited to experiences with social support (for example, Harrison & Harrington 2001; Hoffmann et al., 2010), psychologists (Dyregrov, 2009), or experiences from bereaved siblings (Dyregrov & Dyregrov, 2005). Although those studies indicate that bereaved adolescents hardly find the help they might need, the barriers and facilitators to various types of help remain unclear. Also, no study has investigated adolescents' experiences with different types of support across modes of death and relationships.

To redress this gap in the literature, this study aimed to investigate the help-seeking experiences of adolescents bereaved by suicide or other cause of death. We investigated positive and negative experiences with both formal (professional) and informal support, and barriers and facilitators to access such support. The study findings on adolescents' grief and mental health are reported in the companion paper (Authors, submitted).

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Method

The Human Research Ethics Committee of the University of New South Wales approved the research project (HC15088), followed by approvals of other organizations related to recruitment. The study adhered to the Consolidated Criteria for Reporting Qualitative Research (Tong, Sainsbury, & Craig, 2007). As this study is part of a larger project, the methodology and

ethical considerations are fully reported elsewhere (Authors, submitted). In brief, we conducted semi-structured telephone interviews with a maximum variation purposive sample (Bryman, 2012) of adolescents who had a family member or a friend die when participants were aged between 12 and 18 years, which was 6 months to 10 years prior to interview. We interviewed 39 adolescents (30 girls) (*M* = age 20.6, *SD* = 3.24, range 13-27; average time since loss = 5 years). We stratified the sample to include a similar number of adolescents bereaved by suicide (*n* = 19) and other causes of death, and an equal number with and without professional help-seeking experiences. More details of the sample are included in the companion paper (Authors, submitted) or available upon request.

The semi-structured interview included three questions on help-seeking: what helped or hindered coping with the loss, what specific experiences had participants with help-seeking, and what could the participants recommend to other bereaved adolescents. We asked open-ended questions, allowing for probes, and follow-up of new information. We conducted a Thematic Analysis (Braun & Clarke, 2016), and used NVivo 10 (QSR, 2014) for analysis and data management.

Results

Adolescents sought a variety of help from a variety of places including professionals, school authorities, church or support groups, or online. We summarize the findings in three themes: *Formal support*, *Informal support* and *School-related support.* Results give equal attention to those bereaved through suicide and other causes of death. Participants' names are fictional.

Formal support

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Adolescents, irrespective of the cause of death, seldom accessed formal support solely on their own initiative. Most often the mother, sometimes the father or a friend, referred them to professional help when the adolescent seemed to be struggling with mental health symptoms rather than with grief. Most adolescents experienced the referral as a positive intervention.

> I think it would have helped if I had gone and seen a counsellor a lot earlier. My mum sent me to a counsellor about three or four months afterwards because she was worried that I was depressed or not coping with my grief and then the counsellor referred me to a psychologist who referred me to a psychiatrist and I was lucky then because the psychiatrist was a huge help for me. She was just an amazing woman who just let me talk about everything that I had been holding off for so long. (Gayle, friend accident)

The majority of adolescents seeking formal support received help from outpatient or community-based services; few received inpatient treatment. Most adolescents found it a challenge to find the support they needed. Often they saw a series of different professionals for a short time. For the adolescent to engage in treatment, it was important that they could connect and relate with the therapist, and be comfortable with the treatment format. A negative experience during the first session(s) often resulted in the adolescent dropping out of treatment, often followed by a time lag before restarting treatment. Hence, one interviewee recommended: "Do not get stuck with one psychologist if you think that they're wrong. Just - it's just like pants. Go out and try and find one that fits." (Rebecca, aunt-godmother suicide).

The barriers to formal help-seeking included self-reliance, lack of knowledge of available resources, a mismatch between the availability of the therapist and the adolescent, distrust in services, sometimes based on a previous experience, and fear of being mistreated or judged, which they sometimes related to their young age. One interviewee said,

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> My mum made me go to a couple of psychologists when I was - it had freshly happened. I was like - I didn't find it beneficial when I went to see them and - I don't know, just - like for me, it didn't feel like the right fit at the time, being 16. … I'd just speak to my mum or I'd just deal with it on my own. (Nancy, brother accident)

Another interviewee said,

> You can't talk about your true emotions because you're too scared because you're going to get called a bastard or something like that. … I don't know of anywhere that you can sort of talk openly without the fear of being seen as someone who is going to kill themselves. (Beatrice, best friend suicide)

Retrospectively some adolescents would have welcomed a more assertive referral, or an active offer of formal support. Those who found a therapist with whom they could connect, and received a suitable therapy offer, reported substantial benefit with their depression, anxiety, or other complaints. For some, treatment helped them specifically to gain insight into their grief process, feelings of guilt, or the context of the death.

> I have talked about it with my psychiatrist, and I've thought about it, and I've realised that it was never my fault. There were too many factors that I couldn't have gotten over it. I was too young to be expected to. I didn't have a psychiatrist. I didn't have a psychologist. She [aunt] didn't lay her problems on me because she knew it would be too much, I'm sure she did. But she was the one person who understood me. I'm not angry at her anymore. I'm not angry at my uncle. I think that everything went wrong. (Rebecca, aunt-godmother suicide)

Interviewees across categories of cause of death identified the factors that contributed to a positive help-seeking experience including aspects that facilitated the connection and the

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relationship with the health professional. Adolescents appreciated the expertise and authenticity of the therapists. They thought it was crucial that the therapist respected them as a person, and normalized their experience and feelings, rather than being pedantic, judgmental or condescending. Confidentiality and having a space where they could talk freely without fear of repercussions was equally important.

> It's not even about understanding because to get into that profession you have to have empathy anyway. But it's more just like being respected I guess. Being held up as a real person and [that's your] what's happening to you and not just being a diagnosis. Not just being their version of you. (Diana, cousin accident, great grandmother, old age)

In brief, bereaved adolescents seem to know little about formal resources or perceive these as not available. They found it challenging to find suitable formal support, and parents were the most likely referrers. The quality of the relationship with the clinician was crucial for the adolescent to comply with treatment.

Informal support

A few interviewees sought informal support from support or church groups, though few groups were available. Attending support groups provided them with opportunities to meet other people with similar experiences, to share and to not feel alone. Some adolescents attended support groups for a limited time; others considered groups as a long-term support, and one interviewee started their own support group. Despite the benefits, adolescents sometimes felt ambivalent towards attending support groups, mainly because of confronting their grief.

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They are really helpful but they can also be quite distressing. … It is obviously confronting because you bring the experience to it every month and you will be confronted with not only your own loss but also with the loss of other people. (Laura, brother suicide)

A few interviewees used informal support in conjunction with formal. They explained how formal and informal support served different purposes. Therapy offered opportunities for working through specific issues whereas a support group provided social support, understanding, and a sense of belonging.

Strikingly, adolescents did not often use the Internet as a source of help or information, irrespective of cause of death. Some stated that they did not need or consider online help, or that online help was not their style. Some used the internet to contact online friends and to obtain information about mental health issues, death, suicide or grief. However, interviewees doubted the trustworthiness of online information, and found it not specifically related to their situation. Adolescents preferred finding acceptance, acknowledgement and support through a personal, face-to-face relationship, rather than through the online offerings.

I did look on the internet a little and then with the [organization] as well – like websites and organisations like that. But yeah, mainly the support was from family and friends and people that I knew that were in my life. (Jessy, friend accident)

There were certain things but they helped but not dramatically. I feel like what helps the most was having someone that I can actually talk to and feel comfortable talking to and no judgement, kind of understands where I'm coming from and that sort of thing. (Ellen, family friend suicide)

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Thus, adolescents reported mixed experiences with informal support, though few support groups were available to them. Adolescents seldom used the Internet as a source of help because they doubted the trustworthiness or found the information to be non-specific or impersonal. Adolescents decidedly preferred face-to-face contacts.

School-related support

Adolescents experienced school support mostly as lacking, unavailable, unknown, or passive, irrespective of cause of death. When support was offered it was mostly seen as insufficient. For example, Rachel who lost her grandfather through illness, said, “When I go talk to my school counsellor, sometimes it doesn't help because most of the answers what she said it's like just get over it.” Some interviewees reported hostile reactions from school, so that they felt punished rather than supported.

Conversely, a few adolescents felt that specific teachers understood or supported them. For example, Heidi, who lost her father through suicide, said, “The teachers were quite understanding - the ones that knew, although I did have a few incidents with some teachers and stuff.”

Barriers to seeking support from teachers included: receiving sufficient support from family and friends, feeling self-reliant, being embarrassed, lacking trust, or doubting confidentiality. Additionally, adolescents perceived teachers and school counsellors as lacking expertise, knowledge or training. One interviewee said,

> There was a counsellor and I did go and see her a few times. I just never felt like she really helped. She was giving me deep breathing exercises and relaxation exercises and that

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> wasn't the kind of help I was looking for. So I only went and saw her a few times. (Gayle, friend accident)

Another interviewee said,

> I've heard now that school counsellors aren't registered psychologists. They're just teachers who have additional training to do like child psychology or something. But I think if I had actually gone to a real psychologist who was certified and deals with death and depression specifically it might have helped me through the grieving process a lot more. (Isabelle, father suicide)

Most interviewees reported that, apart from missing one or more days to attend the funeral and occasionally having emotional breakdowns, their school performance was unaffected by the death. One interviewee changed schools citing a religiously inspired judgmental and intolerant reaction after the death; one interviewee attended school irregularly, and another's school grades dropped dramatically due to the death coinciding with family conflicts. For others, attending school provided opportunity to meet friends and find distraction.

Thus, these bereaved adolescents reported mixed experiences with support offered through school. Overall, adolescents perceive school counsellors as unqualified and doubted the confidentiality.

Discussion

This study found important barriers and facilitators to adolescents seeking help following bereavement. It highlights the importance of parental involvement in referral for professional help.

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Even then this referral was delayed. Alarmingly, this study identified a lack of trust in the support provided by school counsellors. We discuss these findings below.

A striking finding was that bereaved adolescents who entered treatment were referred, primarily by the mother, mostly because of mental health symptoms. These adolescents experienced the referral as a positive intervention. Even though adolescents are gaining independence from parents and developing personal identity, which coincides with increased importance of peer relationships, for grief or mental health issues, a parent apparently remains the primary referrer. This adds to findings from mental health research indicating that family, especially parents, more than friends, are the major facilitators of professional help-seeking among adolescents (Rickwood, Mazzer, & Telford, 2015; Ryan, Jorm, Toumbourou, & Lubman, 2015). Given that parents initiated the referral because of concerns for mental health symptoms, the parental intervention may have been appropriate.

Referral to professional care was delayed for many adolescents. Reasons for not seeking help included feelings of self-reliance, relationships with peers or family, lack of knowledge of services, and mental health literacy. This finding extends results from other qualitative studies (for example, Silvén Hagström, 2013) that experiencing a suicide death affects the relationships of bereaved adolescents, resulting in fewer close relationships and more avoidance, which may hinder adolescents' professional help-seeking. Also research related to mental health and suicidality shows that adolescents either do not talk about their mental health concerns or confide with a few friends or parents (Rickwood et al., 2015). As in our sample, girls are more likely to seek professional help. Girls also have more mental health literacy than boys (Coles et al., 2016). The findings suggest that addressing self-reliance and mental health literacy, especially among boys, may improve help-seeking.

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Barriers to adolescents' formal help-seeking in this study resembled those of help-seeking in the realm of mental health and suicidal behaviour (Rowe et al., 2014; Spence, Owens-Solari, & Goodyer, 2016). Barriers include high reliance on family, friends or self; attitudes such as feeling ashamed; limited knowledge of services; difficulty identifying symptoms of mental illness; or perceiving or minimizing symptoms as transient thus not requiring professional attention. Our findings confirm a comment of Summerhurst, Wammes, Wrath, and Osuch (2017) that adolescent struggles with mental health issues are more related to issues of control and self-reliance than with feelings of stigma, which is understandable as self-control and gaining independence are core characteristics of adolescence.

The facilitators to seeking help our study identified include positive past help-seeking experiences, social support, encouragement from others, confidentiality and trust in the provider, which adds to findings of adolescent mental health studies (Freake, Barley, & Kent, 2007; Gulliver et al., 2010). As parents are important referrers, the mental health literacy of parents also is identified as an important barrier for adolescents receiving professional help (Gould et al., 2009). The findings indicate that improving parental encouragement and the trustworthiness of services are crucial to enhance help-seeking of bereaved adolescents.

A core issue related to the helpfulness of formal support for the bereaved adolescents was connecting with a therapist who had a genuine interest in their experiences. This view was voiced many times, and adolescents distinguished factors that contributed to a positive or negative encounter with therapists. Lack of connection with the therapist is likely to result in rapid discontinuation of treatment (which was also observed by Dyregrov, 2009), lack of motivation to seek or to accept other treatment offers, and reinforcement of self-reliance. Conversely, Buston (2002) and Freake et al. (2007) emphasized the importance of the quality of the contact with mental

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health services. In addition, adolescents in our study voiced their expectations towards therapists. They expect to be met with respect and authenticity, and highlight the importance of the relational aspects, such as allowing them to talk, listening with empathy, and providing support and understanding. Also, adolescents expect clinicians to be trained and qualified to work in the area of death and bereavement. Importantly, once it 'clicked', adolescents felt helped, to the extent that some reported it saved their life.

The study revealed unique findings on school-related support. These adolescents were critical of help received through their school. Whereas some bereaved adolescents were happy with the support from particular teachers (reinforcing the pattern of selective sharing), most adolescents experienced a lack of, or passive support, and some adolescents experienced hostile reactions. Adolescents saw school counsellors mostly as teachers who attended a psychology course, and not as clinicians bound by professional confidentiality. This perception helps to explain the adolescents' reluctance to seek their help. Teachers themselves have identified a lack of proper training (Lam & Hui, 2010). Also, the death of a student may affect the school staff as much as the students (Cox et al., 2016); hence, the study findings reveal the necessity of training and pro-active preparation for the whole school community to deal adequately with a (suicide) death.

Bereaved adolescents used formal and informal support, though few support groups were available. Both types of support served a distinct purpose: working through specific issues, and providing social support and a sense of belonging, respectively. This finding confirms findings from studies of bereaved adults which have stressed the importance of communication and practical support from family and friends (McKinnon & Chonody, 2014; Wilson & Marshall, 2010). Others have highlighted that professional support may decrease negative grief feelings (Schneider, Grebner, Schnabel, & Georgi, 2011). Given that bereaved adolescents in this study

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shared their experiences with a limited number of people, it may be that suicide bereaved adolescents struggling with feelings of guilt and the ‘why’-question, may receive less social support. Hence, our findings indicate that professional support may be a much-needed auxiliary, and point to a need to enhance informal support. Further research on the relationship between informal and formal support for bereaved adolescents is needed.

Despite the omnipresence of the internet in daily life, the study uncovered that few bereaved adolescents used it as a source of support. Issues of trustworthiness and relevance appeared to be the main barrier. Also, Burns and Rapee (2006) suggested that adolescents consider that serious problems require face-to-face rather than online support, and research suggests that boys, when encouraged to seek help by family members, are more likely directed to face-to-face services (Rickwood, Webb, Kennedy, & Telford, 2016). The Australian Child and Adolescent Survey of Mental Health and Wellbeing reported online support is used the least among all types of support (2%), whereas health services (14%) are the most frequently used (Lawrence et al., 2015). Other research confirms these findings. According to Mission Australia (2017) more than half of adolescents use the Internet for mental health issues; mainly for social networking and information. Burns, Davenport, Durkin, Luscombe, and Hickie (2010) showed a contradiction: 85% would recommend the Internet to others whereas only 25% could identify information important to them. Examination of the availability and trustworthiness of online resources for people bereaved by suicide shows that it remains a question whether all bereaved persons may find resources according to their needs (Krysinska & Andriessen, 2017). The on-line life of adolescents is a constant and changing factor in today’s society. Urgent attention is needed to the design and presentation of online material on the topic of grief and bereavement. Such design requires the

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input of adolescents themselves to develop a format that is relevant, acceptable, adaptable, and feasible.

Familial support or psycho-education seems indicated to address the impact of a death on the psychological, social and familial life of adolescents (Andriessen et al., 2017; Sandler, Tein, Wolchik, & Ayers, 2016). A paradox that emerged from this study, is the role of the family as an important environment for bereavement support, and encouragement for adolescent help-seeking. At the same time, adolescents may experience tense or ambivalent familial relationships, or even perceive their family as a source of problems. As such, the adolescents' expectation that clinicians are skilled to deal with the complexity and context of adolescent bereavement seems justified.

The study entails a few limitations. We interviewed voluntary participants, mostly girls, who may be more verbally skilled, or more used to talking about their experiences, than boys or other non-participants. Also, telephone interviews were up to 10 years after the death. However, several participants spontaneously stated that participation provided an opportunity to talk about the death, which they had not for some time. It is also possible that those who volunteered are those who have evolved the most since the death, e.g., have experienced the most personal growth, whereas those who are distressed or suffer from depression might be less likely to volunteer. Yet, in order to capture a wide variety of experiences, the study recruited a large maximum variation sample with participants who had experienced a death between as short as 6 months to ten years ago, resulting in a rich data set from help-seeking and non-help-seeking adolescents.

The study revealed crucial issues affecting the help-seeking of bereaved adolescents. Adolescents can provide a critical appraisal of both positive and negative experiences with help-seeking, and their perceptions of barriers or facilitators. Encouragement from parents to seek professional help, more than from friends, is an important facilitator. Those who could connect

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with a therapist were satisfied with the help received, whereas experiences with online support were mixed. A major finding of this study is lack of trust adolescents place in their school community. Given the strong role the school plays in an adolescent's life urgent attention is needed to the training of school counsellors and the school community in relation to bereavement support. The importance of confidentiality to adolescents cannot be ignored.

The availability of both formal (i.e. professional) and informal (support groups) support is important as these serve different needs. Findings were similar across both adolescents bereaved by suicide and other causes of death. However, as those bereaved though suicide can receive less social support, professional help is a much-needed auxiliary. The study findings highlight the importance of a parental/family component in adolescent bereavement support, and a need for training of clinicians and informal caregivers.

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