Pilot investigation into the need and feasibility of a psychoeducation and support group for male caregivers of those with Huntington's disease

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Abstract

The psychosocial sequelae of caregiving in Huntington's disease (HD) have been shown to be extensive, even in comparison with other progressive neurological disorders. Based on observed clinical need, this investigation aimed to identify psychoeducational and emotional support needs of male HD caregivers and to explore the feasibility and utility of a carer support group. Six male caregivers completed quantitative measures assessing depression, anxiety, carer burden, and carer support needs. The men participated in two education and support group sessions, four weeks apart, which were developed with consideration of male support preferences. Qualitative themes arising in these sessions were documented. Questionnaire results showed overall low levels of psychological distress and carer burden. Despite this, the group sessions facilitated disclosure of significant emotional, practical, and relationship challenges arising from HD. Further, a range of psychoeducational and emotional support needs were identified on quantitative and qualitative assessments. Participants strongly endorsed the format of the group and the benefits of participation, highlighting in particular the importance of meeting other men who understood the experience of living with a spouse with HD.

Keywords Huntington's disease · Dementia · Depression · Caregivers · Group psychotherapy · Self-help groups

Introduction

There is an emerging literature describing psychosocial aspects of caregiving in Huntington's disease (HD; e.g., Aubeeluck 2005; Domaradzki 2015; Kaptein 2007; O'Connor 2008; Simpson et al. 2016; Williams 2009). Caregivers of those with HD have reported higher levels of anxiety and depression and a greater negative impact on marital and other social relationships compared to caregivers of those with other progressive neurological disorders (PNDs) (McCabe et al. 2009; O'Connor et al. 2008). Caring for a person with HD may carry particular challenges arising from neuropsychiatric changes, such as loss of empathy (including for the caregiver's needs), limited insight into the extent of impairment, aggression and apathy (Fisher et al. 2014; Kaptein et al. 2007; Simpson et al. 2016; Williams et al. 2009). The lengthy course

of illness and younger symptom onset may also contribute to cumulative losses and strains (Domaradzki 2015; Simpson et al. 2016).

Our service is a publicly funded state-wide service which provides specialist care for those with Huntington's disease, incorporating primary and secondary consultation, education and participation in national and international research projects. The aim of the HD service is to enhance the quality of life of patients and families affected by HD through planning, coordinating and delivering a high level of multidisciplinary care to meet their health, psychosocial and disability support needs, throughout the different stages of HD (i.e. pre-symptomatic to advanced stages). Patient care is provided predominantly through outpatient appointments (face-to-face or telehealth), with some access to inpatient beds. Disciplines include neurology, psychiatry, specialist neurology nursing, neuropsychology, clinical psychology, speech pathology, dietetics, social work, occupational therapy, physiotherapy, music therapy and pastoral care. Caregivers and family members are actively engaged and supported as integral partners in the care of those with HD. A central role of the service is the HD nurse consultant,

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providing a consistent point of contact for the patient and their family, also coordinating their multidisciplinary care.

At our HD clinic, it was observed that a number of male HD caregivers were making regular contact with the HD nurse consultant seeking information and support. This contact might be considered unexpected in light of the well-established finding that men are reluctant to seek assistance, including in the context of caregiver stress (Coe and Neufeld 1999; Greenwood and Smith 2015). It suggested an unmet need amongst these male HD caregivers for additional education and support. We wondered whether addressing this need—in a context which enabled male HD caregivers to meet other men in similar circumstances—could support and enhance their caregiving experience. At this time, there were no local HD caregiver group programs within our service or elsewhere within the state.

Gender differences in the experience and approach to the caregiving role have been identified in research in the dementia field (McDonnell and Ryan 2013; Robinson et al. 2014). Caregiving can challenge traditional notions of masculinity (Baker et al. 2010), and male caregivers may attempt to preserve this, for example, by viewing the role as ‘work’ to be completed (McDonnell and Ryan 2013). Male dementia caregivers have typically been shown to report less distress than women (McDonnell and Ryan 2013; Robinson et al. 2014), although the risk of depressive symptoms in male caregivers increases with the presence of neuropsychiatric symptoms in those with dementia (Valimaki et al. 2009). Male caregivers may also have particular preferences for support, with studies showing that men tend to prefer a focus on information and problem-solving, rather than on emotional expression (Greenwood and Smith 2015). There has been no prior investigation into the experiences and support needs particular to male caregivers in HD.

Research examining caregivers of those with other PNDs has pointed to the benefits of caregiver support groups for emotional and social functioning (Chien et al. 2011; Coe and Neufeld 1999; Dickinson et al. 2017; Piersol et al. 2017; Ugalde et al. 2017; Walter and Pinquart 2019). For example, research on caregivers with dementia has shown that psychoeducation and support group interventions have small to moderate effects on caregiver burden, depression, subjective well-being and knowledge (Chien et al. 2011; Dickinson et al. 2017; Piersol et al. 2017; Walter and Pinquart 2019). Psychoeducation delivered in a group format that also includes opportunities for active skill development has shown to be associated with greater effectiveness in these domains (Dickinson et al. 2017; Walter and Pinquart 2019). In addition, multicomponent interventions, particularly those which incorporate both educational, therapeutic and support components, may be most effective in maintaining the psychological well-being of caregivers (Dickinson et al. 2017). There is, however, no such similar research in the HD field.

In this pilot investigation, two support group sessions were conducted with the aim of (i) identifying the psychoeducational and emotional support needs of male caregivers of spouses with HD and (ii) providing an initial indication as to the feasibility and utility of a support group for male HD caregivers in the context of a Victorian specialist multidisciplinary HD service.

Methods

Seven men who had contacted with concerns about a spouse with HD were invited to participate. Six men provided written informed consent and attended the first session (mean age = 65 years, range = 52–84; mean marriage length = 34 years, range = 14–56). Five participants attended the second session. All spouses were in mid- to late-stage HD, with total functioning capacity scores ranging from one to five (Shoulson and Fahn 1979). The group program was based on a caregivers’ support group for those with motor neurone disease (Ugalde et al. 2017), with adaptations made for HD and to reflect male support preferences. Two 2-h sessions, a month apart, were conducted by an HD nurse consultant and a clinical psychologist (Supplementary Table 1).

To elucidate the psychoeducation and emotion support needs of participants, (i) quantitative questionnaires were administered and returned in session 1, including the Depression, Anxiety and Stress Scale-21 (DASS-21; Lovibond and Lovibond 1995), the Carer Burden Scale (based on Zarit et al. 1980) and the Carer Support Needs Assessment Tool (CSNAT; Ewing et al. 2015), and (ii) qualitative data were gathered by documenting the experiences discussed in group sessions and identifying themes. Specifically, facilitators took notes of discussion through the sessions and reviewed these together immediately afterwards to ensure consistency and comprehensiveness. Thematic analysis was undertaken by the first author. A modified phenomenological approach was followed, which involved reflecting on the meaning of text, including similarities and differences in lived experiences, summarising descriptions of text in a table and identifying core themes (Smith 2003). To investigate the perceived acceptability and feasibility of the group, participants completed written evaluations and participated in a group feedback meeting with an independent clinician.

Results

Psychoeducation and emotion support needs

Responses on the DASS-21 showed low levels of psychological distress. Specifically, four participants responded within the ‘normal’ range across all subscales, while remaining

responses were restricted to the ‘mild’ and ‘moderate’ ranges. Similarly, on the Carer Burden scale, participant responses fell within the ‘mild-moderate’ and ‘none-minimal’ ranges ($n=5$ and $n=1$, respectively); no responses fell in the ‘moderate-severe’ or ‘severe’ ranges.

On the CSNAT, the domains of additional need which were most frequently endorsed (i.e., by at least five participants) included the following: ‘knowing what to expect in the future when caring for your relative’, ‘understanding your relative’s illness’ and ‘dealing with your feelings and worries’. Several areas of need were identified by three or four participants, including the following: ‘having time for yourself in the day’, ‘knowing who to contact if you are concerned about your relative’, ‘looking after your own health (physical problems)’, ‘equipment to help care for your relative’, ‘practical help in the home’, ‘getting a break from caring overnight’, ‘talking with your relative about his or her illness’, ‘providing personal care for your relative’ and ‘managing your relative’s symptoms, including giving medicines’.

Themes which arose in group sessions are presented in Table 1, and these are reflective and expand on the findings of the CSNAT.

Acceptability and feasibility of the support group

All participants rated the sessions as ‘excellent’ overall and stated that they would like to participate in further sessions. All participants strongly agreed that ‘the information provided by presenters was helpful to me’ and that ‘the level of opportunity for sharing between participants was right for me’. Participants strongly agreed ($n=4$) or agreed ($n=1$) that ‘the focus of the sessions was right for me’.

Participants varied in their preferences for the frequency of future sessions (bi-monthly to six-monthly). Topics of interest included funding and financial advice, children’s risk of HD, genetic testing and methods to improve the well-being of caregivers.

Qualitative verbal responses provided useful feedback regarding the group content and format (Table 2).

Discussion

The first aim of this pilot investigation was to explore the psychoeducational and support needs of males providing care to their spouses with HD. Quantitative psychological questionnaires showed low levels of psychological distress and mild to moderate levels of caregiver burden, consistent with research on male caregivers in other neurological illness groups (McDonnell and Ryan 2013; Robinson et al. 2014). It has been previously suggested that distress may be under-reported due to male cultural biases against showing vulnerability (Baker et al. 2010; Brodaty and Donkin 2009).

This may have been occurring to some degree in our sample, given that numerous psychoeducational and emotional support needs were identified on the CSNAT, despite the relatively low reported levels of psychological distress and carer burden. Further, many difficult emotions were reflected in qualitative group discussion themes, such as guilt, fear, loneliness and loss. The experience of a supportive group environment may have facilitated the identification and exploration of emotional issues.

Participants engaged well with the group material and spoke openly about a range of aspects of their caring role. Factual information about HD was endorsed as extremely beneficial, consistent with expectations that this content-type would facilitate group engagement (Greenwood and Smith 2015). The challenges of responding to neuropsychiatric symptoms and dealing with an uncertain prognosis were highlighted as requiring education and support, reflective of suggestions that these are particularly difficult aspects of caring for a person with HD (Simpson et al. 2016; Williams et al. 2009). While participants indicated that they were holding on to a sense of being in a partnership with their spouse, as per previous reports (e.g. Domaradzki 2015), there was acknowledgement of changes in relationship dynamics, with significant spousal dependence and, at times, feelings of aloneness in the relationship. Participants described significant but understandable barriers to self-care, including time restrictions, a sense of guilt and an awareness that time left with their partner was limited. They reported benefit in considering a rationale and strategies for overcoming these barriers.

The second aim was to explore the acceptability and feasibility of the psychoeducation and emotional support group. All participants strongly endorsed the value of the group and stated they wanted the group to continue. The format of the group was supported, with all participants strongly agreeing that the information provided was useful and that the level of opportunity for sharing was appropriate. Our observation was that the provision of practical information provided an anchor around which the discussion of emotional material could occur. Consistent with the reported preferences of men for information (Greenwood and Smith 2015), topics desired for future sessions largely pertained to planning for the future.

During the group feedback, most participants indicated that they had never met anybody in the same situation and were effusive about the opportunity to do so. Since HD is a relatively rare condition, caregiving may be a particularly isolating experience, and a support group may provide some antidote to this isolation. Some men indicated that they preferred a men’s only group and reported that this helped them feel more comfortable with self-disclosure, although this was not a uniform view, and others described it as ‘strange’. While further research is needed to determine whether single

Table 1 Qualitative themes arising in the two education and support group sessions

Broad theme	Details of theme
Appreciation of information about HD	<ul style="list-style-type: none"> Appreciation was expressed for the information provided about HD, with many stating that this was the first time they had received an overview of the disease
Concerns about an uncertain future	<ul style="list-style-type: none"> Recognition from some that their partners were in a later stage than what they had realised Recognition of the need for future planning ('needs to be done') and the difficulty of addressing this due to its confronting nature and competing priorities The difficulty of anticipating the course of HD, resulting in uncertainty and continual experiences of change and loss
Challenge of dealing with neuropsychiatric symptoms	<ul style="list-style-type: none"> Difficulty with obsessional behaviours, such as compulsive buying and persistent phone calls Feeling uncertain about how to manage such behaviours, and wishing to avoid taking a directive role and causing conflict Having times of feeling 'in control', involving sticking to a tightly structured routine, and 'out of control', when routine was disrupted and caused significant disturbed behaviour in one's partner
Self-care: acknowledgement of benefit and identification of significant barriers	<ul style="list-style-type: none"> Some participants reported doing self-care homework while others indicated they had not Self-care activities (e.g. exercise, reading, and listening to music) were experienced as renewing energy Barriers to engaging in self-care were identified as (i) limited time, with activities 'lost' due to increased caring demands; (ii) perceiving that taking time away from one's HD partner was 'selfish'; and (iii) wishing to spend available time with one's partner due to their foreshortened life A link was drawn between capacity to care over a longer period and retaining quality in relationship with ongoing self-care. 'It feels selfish, but I know it's important'
Shifting relationship dynamics	<ul style="list-style-type: none"> Identification of changes in the nature of the relationship: <ul style="list-style-type: none"> Feeling that one's partner with HD remains an equal ('side by side') but recognising their increased reliance on them in the relationship ('sitting on my shoulders', 'not a burden, it is just reality') Feeling more 'alone' due to spouse sleeping a lot, leading to mixed feelings as this both provided time for recovery or personal pursuits (e.g., being in the shed, watching a movie) and also resulted in feelings of isolation
The consuming nature of caring	<ul style="list-style-type: none"> Life at home revolving predominantly around providing care, routine and support for one's partner Losses associated with being so task-driven. One participant commented 'we don't often stop and smell the roses'. He spoke about noticing flowers placed in a vase by a carer. After he commented on their beauty, he was told by the carer: 'they are from your garden'
Paid work as a 'break'	<ul style="list-style-type: none"> Living 'two' lives: work and home Work (paid and unpaid) was identified as a means of taking a permissible 'break' from caring
HD in the family	<ul style="list-style-type: none"> Prior experiences of losing family members to HD HD being a forbidden topic in the family Decisions about the genetic testing of children Difficulty dealing with the responses of other family members to HD Feelings of uncertainty about how to address these issues

gender groups are preferable to combined groups, our experience was that a male-only group offered the opportunity to tailor the material and approach to men, both providing information and offering a space where participants could easily speak about their experiences and feel understood.

Study limitations and future directions

This pilot project was limited in scope and generalisability due to the small sample size, the limited number of

sessions (two) and the inclusion of men who were actively engaged with the HD service. The identified low level of distress may be reflective of this selective sample who readily reached out for support from an HD service. Given the potentially isolating and demanding nature of the caregiving role in HD, as well as the previously identified reluctance of men to reach out for assistance (Coe and Neufeld 1999; Greenwood and Smith 2015), there is a significant need to develop interventions for those who do not readily engage with an HD support service. Such

Table 2 Qualitative verbal responses to the education and support group structure and format

Theme	Details
Responses to men's only group	<ul style="list-style-type: none"> • Some men stated that having a male-only group was comfortable and enjoyable, while another commented that it was 'a bit strange' • One pointed out that 'men's sharing has specific characteristics', highlighting that it was easier to 'open up' in a group of men • It was stated that women would not have detracted from the connection in the group, but might have changed some of the conversations • All indicated that they would attend a mixed gender group if it was on offer
Appreciation for care, information and support received	<ul style="list-style-type: none"> • Appreciation for coming to a place where HD was understood • The benefits of meeting others in the same situation, generally for the first time, including 'the opportunity to share challenges as a carer of an HD person' • Appreciation of the facilitators' knowledge ('they know their stuff') and approach ('know how to talk without being patronising') • The different professional backgrounds of the facilitators were complementary in addressing practical (nursing) and emotional support (psychology) needs • The group dynamic as 'comfortable', 'non-threatening' and 'honest' and that 'knowing there are people to listen and support us gives us strength'
Structure of group	<ul style="list-style-type: none"> • Size of five to six participants was viewed as good • Having sessions a month apart was beneficial; 'didn't feel bad taking time off work that far apart', 'gave good thinking time' • Having the group in the middle of the day was identified as hard for those who are working, but 'achievable' as 'you make the time because you want to be here' • Participants indicated that they would love to keep the group going and will stay in contact each other regardless

interventions may need to take a proactive approach to facilitating initial engagement with the HD service, such as regular phone calls. There is also a need to adapt the current study design to address the needs and preferences of female caregivers, which could alter the format of the group, for example, with increased unstructured opportunities for emotional disclosure (Helder et al. 2002; McDonnell and Ryan 2013).

Participation in the caregiver support group was offered only to those who could physically attend the HD specialist service. Geographical barriers to participating in such a program may be significant, particularly as the low prevalence of the disorder means that affected families may be geographically spread. Internet-based programs are one way of addressing this geographical barrier and therefore warrant further investigation. Internet-based programs may also be preferred by caregivers who are local to the service, given the potentially reduced time and effort involved to engage and the ability to continue providing care while participating.

This pilot project has served as the basis for an ongoing psychoeducation and support group for male HD caregivers within our service, open to new attenders and with sessions occurring approximately each three months. Topics have been generated by the men and have covered relationship changes, residential care placement decisions, incontinence, apathy/cognitive changes, respite options, advance care planning, communication changes

and manual handling. These topics required involvement from a number of multidisciplinary team members as co-facilitators (HD nurse consultant, clinical psychology, neuropsychology social work, physiotherapy, speech therapy). This illustrates how a caregiver support group model can be put into place within a multidisciplinary program that incorporates aspects of health and social care, and which may be uniquely placed to address the complexity and diversity of caregiving concerns in HD. Service-provision contexts differ both internationally and nationally, so as this under-researched area evolves, it will be necessary to identify which caregiver support models best suit different service contexts.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s12687-021-00535-2>.

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Author contribution All authors contributed to the study conception and design. Material preparation, session facilitation and data collection were performed by Ruth Hosken and Sarah Velissaris. Analysis was performed by Sarah Velissaris and Cathy Gluyas. The first draft of the manuscript was written by Sarah Velissaris, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Declarations

Ethics approval Ethical approval for the study was granted by the Research Ethics and Ethics Committee at Calvary Health Care Bethlehem (ref: 17102603). All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare no competing interests.

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