Can physical activity support young people after the death of a parent? The BABYSTEPS Project

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Parental bereavement in the public eye

• Prince William (aged 15); Prince Harry (aged 12); Professor Green (aged 24); Calum Best (aged 24); Bobbi Kristina (aged 19 – deceased by 22)

• Parental death can increase risk factors such as social withdrawal/isolation, depression, anxiety, alcohol misuse, drug use and suicide ideation.

• It can often take years, even decades to seek help and support
Programme of research – BABYSTEPS project

• 1999 - Lost dad at 20 years old

• 2015 – children lost their dad (aged 13 and 20 years old) – no idea how to help them

• 2016 moved to UoB – Sport and Physical Activity Department

• Received funding for programme of research on parental bereavement

Belonging
After
Bereavement in the Young

Support
Through
Exercise
Physical activity and Sport
Parental bereavement in the UK

In 2016:

- 23,600 parents died
- Leaving 41,000 dependent children
- A parent dies every 22 minutes
- 1 in 29 children have been bereaved of a parent or sibling
- Roughly 1 person per class has been parentally bereaved
Grief outcomes

• Differ in nature and intensity

- Affective
  - Guilt
  - Anger
  - Anxiety
  - Depression

- Cognitive
  - Resilience
  - Concentration
  - Suicide ideation
  - Well-being

- Behavioural
  - Substance use
  - Isolation
  - Suicide
  - Aggression

Post traumatic growth
Post traumatic stress

Post traumatic growth
Post traumatic stress

Post traumatic growth
Post traumatic stress

Post traumatic growth
Post traumatic stress
Physical activity and Grief-related outcomes

• Physical activity has been shown to be beneficial for improving mental health and well-being (Hamer et al., 2009)

• Decreases depression/ anxiety
• Improves self-esteem/ quality of life
• Helps control aggression
• Helps with isolation

• Evidence it can support bereavement
  • (Mind over Marathon, 2017)
RQ: Can physical activity support bereavement?

A systematic review of the literature
Aim: To examine if sport and physical activity can support grief outcomes of bereaved individuals.

Year of search - 2019
Records identified through database searching (n = 829)

Additional records identified through other sources (n = 2)

Records after duplicates removed (n = 606)

Records screened (n = 606)

Records excluded (n = 567)

Full-text articles excluded, with reasons (n = 19)
- Investigating physical functioning not physical activity (n=1)
- Physical activity not mentioned (n=11)
- Cancer survivors using physical activity and experiencing bereavement but no relationship. (n=1)
- No bereavement (n=2)
- Conference abstract or review (n=2)

Full-text articles assessed for eligibility (n = 39)

Studies included in qualitative synthesis (n = 20)
Systematic review: Results – N=16,612

Parental Deaths
- Brewer and Sparkes (2011a) UK
- Brewer and Sparkes (2011b) UK
- McClatchey et al., (2012)
- Zhao et al., (2014)

Patient Deaths
- Granek et al., (2017)
- Granek et al., (2016a)

Spousal Death
- Grimby et al., (2008)
- Kang and Yoo (2007)
- Richardson (2010)

Still-Birth
- Huberty et al., (2014b)

Multiple bereavement
- Simpson et al., (2014)
- Li et al., (2015)

Later Life bereavement
- Chen et al., (2005)

General bereavement
- Phoenix and Orr (2017) UK

Caregiver bereavement
- Zhang et al., (2008)

Residential weekends
Martial arts or Yoga
Dan Jeon breathing and stretching
Running or Walking
Non-Specified

11 (5/11 exp) Quantitative
9 Qualitative
Parental bereavement studies: Grief outcomes identified

- Brewer and Sparkes (2011a)
- Brewer and Sparkes (2011b)
- McClatchey et al., (2009)
- McClatchey et al., (2012)
- Zhao et al., (2014)

**Builds Resilience**
- Improves self-esteem
- Decreases loneliness
- Meeting others in similar situations
- Distraction
- Freedom
- Retaining Memories
- Family cohesion
Systematic review: Conclusions

• Limited research investigating parental bereavement and physical activity

• Variety of activities - often non-specified activity or residential weekends

• Qualitative research with small sample sizes

• Lack of interventions in this area

• No standardized way of measuring grief outcomes (x16 used)
RQ: What support is available for young people who have been bereaved?

National and Local Bereavement Services
- CHUMS
- Child Bereavement UK
- Cruse

Types of Services provided
- Individual counselling
- Group counselling
Aim and Method: Study 2

Aim:
To reveal what current physical activity provisions are in place for young people (WHO definition 10-24 years) who have been bereaved.
To confirm how many young people access bereavement support services.

Method:
- Bereavement organisations (10-24yrs)
- Completed an online survey
- Contacted via email + phone
- Websites search for information
Participating organisations

373 Bereavement organisations identified
  - 167 Participated
  - 206 did not participate

Reasons for non-participation
Not successfully contacted (N=139)
Declined to participate (N=23)
Adult or young children (N=12)
No bereavement support (N=19)
Signpost or helpline (N=13)
Physical activity offered to support bereavement in young people.

- Yes: 80.8% (n=135)
- No: 16.8% (n=28)
- Not Answered: 2.4% (N=4)
The types of physical activity offered by bereavement services.
Current provision: Results

Number of young people who accessed bereavement organisations

- Referral: 5334
- Approximate: 105300
- Accurate: 8258
Current provision: Conclusions

• 80.8% of organisations don’t offer physical activity

• Residential weekends are the most offered type of activity

• Many organisations do not know how many young people use their services

• There is no current routine way in the UK to collect this data
Overall conclusions

- Systematic review highlights that research is limited
- No experimental research specifically using physical activity to support parental death
- Studies often fail to mention which physical activity
- Wide variety of grief outcomes used
- Majority of services do not offer physical activity
- Organisations do not know how many young people access their services

What’s needed?

- More research with target population
- More interventions with proper evaluation
Future direction

• Just completed
  • x2 qualitative pieces of work
    – PA and parental death
  • x1 online survey

• Intervention with Active Partnerships and Local Authority - Luton
Belonging
After Bereavement in the Young

Support Through Exercise Physical activity and Sport

Thank you

With thanks to ISPAR (funding), Jane Williams (PhD candidate), Dr Gillian Shorter, Dr Neil Howlett, Dr Julia Fruer (co-supervisors and collaborators)
Review data
<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Title</th>
<th>Country of Study</th>
<th>Study type (Methods)</th>
<th>Sample Size</th>
<th>Age Range (Mean)</th>
<th>Gender</th>
<th>Type of bereavement</th>
<th>Grief Outcome (Measure)</th>
<th>Type of Physical activity (Measure)</th>
<th>Main Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brewer, J D., Sparkes, A C. (2011a)</td>
<td>Young people living with parental bereavement: Insights from an ethnographic study of a UK childhood bereavement service</td>
<td>United Kingdom</td>
<td>Qualitative (Interviews and Observations)</td>
<td>13</td>
<td>9-25 years</td>
<td>Male (n=6) Female (n=7)</td>
<td>Parental</td>
<td>Aggression, anxiety depression.</td>
<td>Martial Arts, Football, Walking, running</td>
<td>Seven key themes: expressing emotion, physical activity, positive adult relationship(s), area of competence, friendships, social support, having fun/humour and transcendence</td>
</tr>
<tr>
<td>Brewer, J D., Sparkes, A C. (2011b)</td>
<td>The meanings of outdoor physical activity for parentally bereaved young people in the United Kingdom: insights from an ethnographic study</td>
<td>United Kingdom</td>
<td>Qualitative (Semi-structured Interviews and Observations)</td>
<td>13</td>
<td>9-25 years</td>
<td>Male (n=6) Female (n=7)</td>
<td>Parental</td>
<td>Anxiety, aggression, panic attacks, stress</td>
<td>Martial Arts, Rugby, Sports, Exercise</td>
<td>4 Key themes: Freedom, Distraction/escapism, retaining memories, family cohesion</td>
</tr>
<tr>
<td>Chen, J H., Gill T M., Prigerson, H G., Figerson, H G (2005)</td>
<td>Health behaviours associated with better quality of life for older bereaved persons</td>
<td>United States of America</td>
<td>Quantitative (Questionnaire)</td>
<td>200</td>
<td>50+ years (66.3 years)</td>
<td>Male (N=53), Female (N=147)</td>
<td>Later Life bereavement</td>
<td>Quality of life, Depression, Sleep (RAND-36)</td>
<td>Exercise [Not Specified](Health behaviour questions)</td>
<td>Exercising 1 or more days per week predicts more quality of life outcomes when practiced consistently</td>
</tr>
<tr>
<td>Study</td>
<td>Participants</td>
<td>Country</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>Gender Distribution</td>
<td>Event</td>
<td>Coping Strategies</td>
<td>Exercise (not specified)</td>
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<tr>
<td>Granek, L., Barbera, L., Nakash, O., Cohen, M., Krzyzanowska, M.K. (2017)</td>
<td>Experiences of Canadian oncologists with difficult patient deaths and coping strategies used</td>
<td>Canada</td>
<td>Quantitative (Online Questionnaire)</td>
<td>98</td>
<td>Female (N=48)</td>
<td>Male (N=50)</td>
<td>Patient Death</td>
<td>Coping strategies</td>
<td>Moreover, apart from the importance of peer support, Canadian oncologists listed a broad variety of coping strategies used in responding to patient death. Given that variety, no single intervention will be suitable for all oncologists</td>
<td></td>
</tr>
<tr>
<td>Granek, L., Barrera, M., Scheinerman, K., Bartels, U. (2016b)</td>
<td>Paediatric oncologists' coping strategies for dealing with patient death</td>
<td>Canada</td>
<td>Qualitative (Interviews – Grounded Theory method)</td>
<td>21</td>
<td>Male (N=10)</td>
<td>Female (N=11)</td>
<td>Patient Death</td>
<td>Coping Strategies</td>
<td>Physical activity (i.e. walking, yoga, running, bike riding, hiking in nature, dancing)</td>
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</tbody>
</table>

"For paediatric oncologists, physical activity was an important coping strategy to 'let off steam' and to ameliorate the emotional pain of patient death. This included regular exercise such as running, biking, yoga, as well as other vigorous activities such as hiking, dancing, and other opportunities to move."
<table>
<thead>
<tr>
<th>Study Title</th>
<th>Country</th>
<th>Methodology</th>
<th>Year</th>
<th>Age Range (Years)</th>
<th>Gender</th>
<th>Additional Factors</th>
<th>Activity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grimby, A. Johansson, Å., Sundh, V., Grimby, G. (2008)</td>
<td>Sweden</td>
<td>Mixed Methods (Questionnaires + Interviews)</td>
<td>51-89</td>
<td>Females and Males (only in group 3)</td>
<td>Spousal Death and Isolation</td>
<td>Walking</td>
<td>Newly bereaved women decrease physical activity and have a reduced perception of being healthy.</td>
<td></td>
</tr>
<tr>
<td>Huberty, J L., Coleman, J., Rolfsmeyer, K., Wu, S. (2014a)</td>
<td>United States of America</td>
<td>Qualitative (Interviews)</td>
<td>19-44</td>
<td>Female (N=24)</td>
<td>Still Birth and Depression</td>
<td>Physical Activity</td>
<td>Women's beliefs about physical activity after stillbirth were coded into the following major themes: barriers to physical activity (emotional symptoms and lack of motivation, tired, lack of time, guilt, letting go of a pregnant body, and seeing other babies), benefits to physical activity (feeling better emotionally/mentally, helping women to cope or be therapeutic), importance of physical activity (working through grief, time for self), motivators for physical activity (body shape/weight, health, more children, be a role model, already an exerciser).</td>
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<tr>
<td>Study</td>
<td>Title</td>
<td>Country</td>
<td>Type</td>
<td>Sample Size</td>
<td>Age</td>
<td>Gender</td>
<td>Event</td>
<td>Condition</td>
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<tr>
<td>Hubert, J. et al., (2014b)</td>
<td>Physical activity and depressive symptoms after stillbirth: Informing future interventions</td>
<td>United States of America</td>
<td>Quantitative (Descriptive exploratory)</td>
<td>175</td>
<td>19-45 years (31.26 years)</td>
<td>Female (N=175)</td>
<td>Still birth</td>
<td>Depression</td>
</tr>
<tr>
<td>Kang, H., Yoo, Y. (2007)</td>
<td>Effects of a Bereavement Intervention Program in Middle-Aged Widows in Korea</td>
<td>Korea</td>
<td>Qualitative (Quasi-experimental design)</td>
<td>27</td>
<td>36–64</td>
<td>Females</td>
<td>Spousal death</td>
<td>Stress, Immune Response</td>
</tr>
</tbody>
</table>

38% used PA to cope with depression. Women reported participating in regular physical activity (at least 150 minutes of moderate activity weekly) before (60%) and during (47%) their pregnancy, as well as after their stillbirth (61%). Of those that reported using physical activity to cope after stillbirth, they did so to help with depression (58%), weight loss (55%), and better overall physical health (52%). To cope with stillbirth, women used walking (67%), followed by jogging (35%), and yoga (23%).

Dan-Jeon breathing sessions, a self-help group activity, and a health check, an experimental group showed significantly greater decrements in grief levels and symptoms of stress over a control group who received only a health check.
<table>
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<tr>
<th>Study</th>
<th>Title</th>
<th>Country</th>
<th>Type</th>
<th>Sample Size</th>
<th>Age</th>
<th>Gender</th>
<th>Intervention</th>
<th>Outcome Measures</th>
<th>Intervention Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Li, J., et al. (2015)</td>
<td>From Body to Mind and Spirit: Qigong Exercise for Bereaved Persons with Chronic Fatigue Syndrome-Like Illness</td>
<td>China</td>
<td>Quantitative (Intervention)</td>
<td>46</td>
<td>23-52 years</td>
<td>Female (N=40) Male (N=6)</td>
<td>Spousal death, sibling death, parental death, other death</td>
<td>Fatigue, depression, anxiety, well-being</td>
<td>Qigong Bereaved participants with CFS-like illness in this study had significantly higher mental fatigue scores and lower physical functioning than did the nonbereaved participants.</td>
</tr>
<tr>
<td>McClatchey, I. S., Vonk, M. E., Palardy, G (2009)</td>
<td>Efficacy of a Camp-Based Intervention for Childhood Traumatic Grief</td>
<td>United States of America</td>
<td>Quantitative (Intervention)</td>
<td>100</td>
<td>6-16 years</td>
<td>Males (N=48), Females (N=52)</td>
<td>Parental death</td>
<td>PTSD, Childhood traumatic grief, canoeing, hiking, treasure hunts, and other play activities.</td>
<td>The results indicate that the short-term, trauma-focused grief intervention reduced traumatic grief and PTSD symptoms among parentally bereaved children. In addition, symptoms of both traumatic grief and PTSD symptoms continued to decline at a 2-week follow-up measurement.</td>
</tr>
<tr>
<td>McClatchey, I. S., Wimmer, J.S. (2012)</td>
<td>Healing Components of a Bereavement Camp: Children and Adolescents Give Voice to Their Experiences</td>
<td>United States of America</td>
<td>Qualitative (Semi-structured interviews)</td>
<td>32</td>
<td>8-17 years (Parent/guardian participant unknown)</td>
<td>Males (N=5), Females (N=27)</td>
<td>Parental death</td>
<td>Traumatic grief and PTSD, Traditional camp activities - canoeing</td>
<td>The categories discovered under the first theme were counselling sessions, memorial service, balloon release, and journaling. The categories under the theme of “traditional camp activities” viewed as most healing were connecting with other campers, canoeing, and the talent show.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>United Kingdom</th>
<th>Quantitative (Cross Sectional)</th>
<th>188</th>
<th>N/A</th>
<th>Male (N=100)</th>
<th>Patient death</th>
<th>Coping strategies</th>
<th>Exercise (not specified)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Female (N=85)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Missing Data (N=3)</td>
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</tbody>
</table>

Common coping strategies included talking, spending time alone and exercise. There was no relationship between respondents’ exposure to previous training and the intensity of emotional or physical responses.

Coping strategies listed, 83.5% of respondents disclosed that talking with others was their preferred method. Having time alone (64.4%) or socialising (36.2%) were also shown to be popular forms of coping; less popular methods included exercise (26.6%) and seeking religious guidance (21.8%).
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title</th>
<th>Country</th>
<th>Methodology</th>
<th>Sample Size</th>
<th>Gender</th>
<th>Event</th>
<th>Symptom</th>
<th>Activity</th>
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</thead>
<tbody>
<tr>
<td>Phoneix, C. Orr, N. (2017)</td>
<td>Analysing exceptions within qualitative data: promoting analytical diversity to advance knowledge of ageing and physical activity</td>
<td>United Kingdom</td>
<td>Qualitative (Narrative constructionism - Interviews)</td>
<td>51</td>
<td>N/A</td>
<td>Males (N=23) Females (N=28)</td>
<td>General bereavement Anxiety, depression</td>
<td>Physical activity (not specified)</td>
</tr>
<tr>
<td>Richardson, V.E. (2010)</td>
<td>Length of Caregiving and Well-Being among Older Widowers: Implications for the Dual Process Model of Bereavement</td>
<td>United States of America</td>
<td>Qualitative (survey)</td>
<td>200</td>
<td>58-91 years (75 years)</td>
<td>Males (N=200)</td>
<td>Spousal death Affect</td>
<td>Social clubs, playing sports Join club since wife’s death (Mean .140), play sports often (mean. 275)</td>
</tr>
<tr>
<td>Simpson, C., Allegra, J. C., Ezeamama, A. E., Elkins, J., Miles, T. (2014)</td>
<td>The impact of mid- and late-life loss on insomnia: Findings from the health and retirement study, 2010 cohort</td>
<td>United States of America</td>
<td>Quantitative (Database - Health retirement study (HRS))</td>
<td>12,759</td>
<td>50-70 years</td>
<td>Male (N=6084) Females (N=3752)</td>
<td>Spousal death, Parental death, child loss, sibling, Insomnia, loss, depression</td>
<td>Active (not specified)</td>
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<tr>
<td>Yoo, Y., Kang, H. (2006)</td>
<td>Effects of a bereavement intervention program on depression and life satisfaction in middle aged widows in Korea.</td>
<td>South Korea</td>
<td>Quantitative (Quasi-experimental design)</td>
<td>27</td>
<td>35 – 64 years</td>
<td>Females (N=27)</td>
<td>Spousal death</td>
<td>Depression, Life satisfaction</td>
</tr>
<tr>
<td>Zhang, B., Mitchell, S. L., Bambauer, K. Z., Jones, R., Prigerson, H. G., (2008)</td>
<td>Depressive Symptom Trajectories and Associated Risks Among Bereaved Alzheimer Disease Caregivers</td>
<td>N/A</td>
<td>Quantitative (questionnaires)</td>
<td>182 (62.8)</td>
<td>Female (N=152) Male (N=30*)</td>
<td>Caregiver death</td>
<td>Depression</td>
<td>Exercise (not specified)</td>
</tr>
</tbody>
</table>
Zhao, J., Chi, P., Li, X., Tam, C.C., Zhao, G. (2014)

Extracurricular interest as a resilience building block for children affected by parental HIV/AIDS

United States of America / China

Quantitative (cross-sectional)

1625

6-18 years

Male
(N=826)
Female
(N=799)

Parental death

Depression,
Loneliness, self-esteem

Sport (not specified)

Extracurricular interest 6 questions

Having extracurricular interest attenuated the negative effect of parental HIV/AIDS on children’s self-esteem and loneliness, after controlling for children’s age, gender, and family socioeconomic status.