

RESEARCH AND PRACTICE: *MIND THE GAP*

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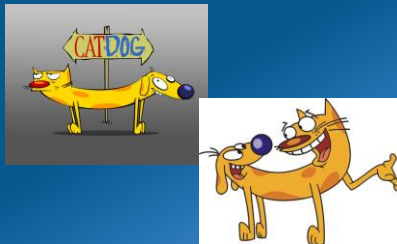
Contribution to the 16th Kaleidoscope Conference,
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30-31 May 2018

STRATEGIC GOALS REGARDING BEREAVEMENT CARE:

- ▶ Provide an open and accessible infrastructure of bereavement care and high quality information re grief and bereavement.
- ▶ Focus interventions on risk groups.
- ▶ Systematically evaluate services.
- ▶ Cherish what works, adapt or dispose of what does not.

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GOALS THAT REQUIRE CLOSE COLLABORATION BETWEEN CARE GIVERS AND RESEARCHERS



STRATEGIC CONSIDERATIONS REGARDING BEREAVEMENT CARE:

- ▶ Provide an open and accessible infrastructure of bereavement care and high quality information re grief and bereavement.

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Many (western) countries indeed seem to have such an infrastructure these days (from palliative care settings to bereavement support organisations)

But there is still a lot of work to be done.....(and being done)

However: the majority of bereaved people seems to rely on family and friends for support and appreciate that much more in terms of helpfulness (Aoun et al., 2018)

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As for high quality information:

"The majority of the information resources [available to the bereaved - HS] draw on the five stages of grief theory (Kübler-Ross, 1969)."

"Most organisations should review the theory behind their information resources in the light of recent developments in the field of bereavement theory and research."

Petrus Consulting (2008). *Review of Bereavement Support Services*

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WHY NOT REACH OUT TO ALL BEREAVED?

- ▶ That has been show not to be effective

Baltes et al. (2014), Butler et al. (2008, 2010), Derogatis et al. (2013), Engel et al. (2013), Garsjole et al. (2013), Kessler et al. (2011, 2013), Suprao et al. (2013), Galat et al. (2015), Wogner et al. (2013), Wiltoeck et al. (2011, 2014)

- ▶ Some of these interventions even tend to have *negative effects*

Wiltoeck et al. (2011)

- ▶ Limited resources etc.

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BASIC QUESTION: HOW DO WE TRACK RISK GROUPS?

A complicated issue, often studied in a simple way (e.g., lack of appropriate comparison groups, isolated variables, sophisticated analyses)


Difficult to translate research findings into clinical practice

A NEED FOR GOOD ASSESSMENT INSTRUMENTS

- ▶ Sealey et al. (2015): A thorough review of bereavement risk assessment measures.
- ▶ Covers 19 measures published 1982 - 2014.
- ▶ Conclusion: "this review is an *important preliminary step* (*italics added*) in improving the assessment of bereavement risk" (p. 577)

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CBCS-STUDY



- ▶ Development of a valid and reliable risk assessment instrument: Indicator of Bereavement Adjustment Cruse Scotland (IBACS)
- ▶ Determine the efficacy (if any) of the CBCS New Service Model of stepped care
 - ▶ Secondary and tertiary intervention
 - ▶ Bereaved initiating contact

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MAGGIE & ME


CATE NEWSOM



2018


STEWART WILSON JOHN BIRRELL

WHAT DOES IT TAKE?



- ▶ Mutual respect, a shared value system
- ▶ Courage
- ▶ Readiness to leave your comfort zone
- ▶ Time, a lot of time

CBCS-STUDY





- ▶ Development of a valid and reliable risk assessment instrument: Indicator of Bereavement Adjustment Cruse Scotland (IBACS)

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THE IBACS

NEWSOM ET AL. (2016) DOI:10.1371/JOURNAL.PONE.0164005





- ▶ A concise semi-structured interview combined with self-report questions
- ▶ Easy to use (after basic training and initial supervision)
- ▶ The score is composed of:
 - ▶ Grief manifestations
 - ▶ Risk factors
 - ▶ Discretionary points

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THE IBACS

NEWSOM ET AL. (2016)



- ▶ A reliable instrument (consistent)
- ▶ Capable of differentiating grief from general psychological well-being (*considering*)
- ▶ Effective for detecting moderate to severe difficulties coping with grief
- ▶ A good diagnostic instrument for assessing concurrent complicated grief (ICG caseness) and 18 months later
- ▶ Easy to use for non-clinicians, both vis-à-vis and by telephone (except for discretionary points)



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THE IBACS
NEWSOM ET AL. (2016)





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THE IBACS
NEWSOM ET AL. (2016)

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THE IBACS
NEWSOM ET AL. (2016)

Interested in the instrument? Contact CBCS at <http://www.crusescotland.org.uk>

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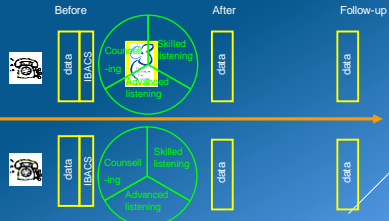
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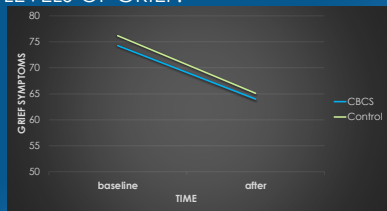
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HOW DID WE ADDRESS THAT?
NEWSOM ET AL. (2017) DOI: 10.1002/CP.21113 (OPEN ACCESS TOO)



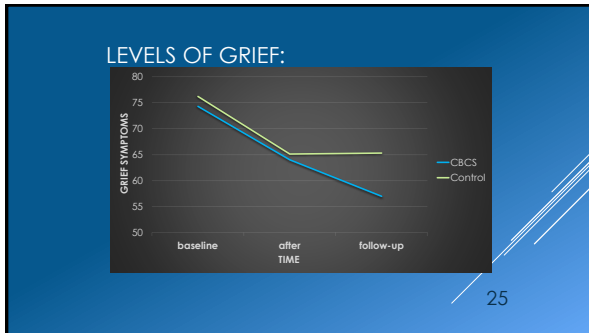
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LEVELS OF GRIEF:




Group	baseline	after
CBCS	~75	~45
Control	~75	~48

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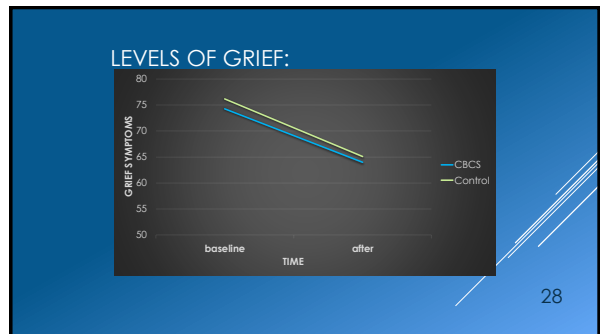


MEANING




- ▶ No effects of intervention *during* CBCS contact
- ▶ But significant improvement *after* counselling finished
- ▶ CBCS counsellors see improvement that *is not* due to counselling

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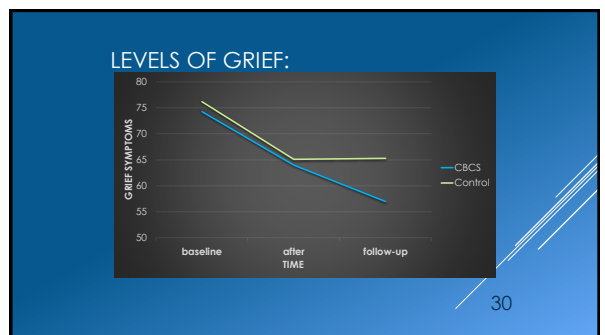


MEANING



- ▶ No effects of intervention *during* CBCS contact
- ▶ But significant improvement *after* counselling finished
- ▶ CBCS counsellors see improvement that *is not* due to counselling
- ▶ They do not see the improvement that actually is a result of counselling

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Don't believe everything you think

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SERENDIPITY RESULTS

(MAKING US ALL REALLY HAPPY AND PROUD)

NEWSOM ET AL. (2017) DOI.ORG/10.1080/10503307.2017.1377359 (AGAIN, OPEN ACCESS)



- ▶ Very low income category overrepresented among CBCS clients
- ▶ Low income strongly associated with risk of higher levels of grief
- ▶ CBCS care was as helpful for very low income group as it was for the others

TOGETHER WE BRIDGED A GAP AND IT WAS (AND IS):

- ▶ Scientifically sound (we believe)
 - ▶ Practically and societally relevant (we see)
 - ▶ More than the sum of its parts (we realize)
 - ▶ Great fun (we know!)
 - ▶ Extremely frustrating (we experience)
- Because yet, CBCS is still struggling for funding



THANK YOU