

發展智障人士生死教育的協作經驗 Concerted Effort in Developing Death Education Service for Persons with Intellectual Disabilities

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東華三院擁抱夕陽服務計劃

- 包括視障長者、嚴重弱能人士，智障人士。
- 服務對象之病患包括末期癌症，末期器官衰竭、嚴重身體機能缺損、晚期腦退化症。





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具體服務

- 照顧在復康中心內患有末期病的院友，使他們有質素及有尊嚴地生活直至離世。





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• 推動生死教育及進行相關研究





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智障人士與家人的雙老現象

智障人士高齡化已有明顯的趨勢
家人也同時在老化中





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智障人士 面對生離死別的機會多了





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但不少人的想法是

- ❑ 智障人士不明白生死，就不要讓他們知，讓他們快樂無憂吧！
- ❑ 讓智障人士知道有親朋死亡，只會令他傷心，不如不說，反正他們很快會忘記。



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- Lavin (2002) 指出智障人士的喪親經歷乃是一個被剝奪哀悼(Disenfranchised grief)的情況
- 參考愛爾蘭有關研究 (MachHale, McEvoy & Tierney 2009)

探討智障人士對死亡概念的認識與喪親經歷，從而設計及評估適切的相關服務。



具體目標

1. 探索智障人士對死亡概念的理解
2. 設計為智障人士提供的生死教育模式
3. 推行及評估為智障人士提供的生死教育
4. 探索智障人士的喪親反應
5. 設計用於評估智障人士的喪親反應行為量表
6. 初步探索量表用於本港智障人士的情況



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死亡概念

- 1) 不能逆轉 (人死不能復生)
- 2) 不能活動 (失去所有活動能力)
- 3) 廣泛性 (人人必有一死)
- 4) 不能避免 (死亡會發生在自己身上)
- 5) 多元因素 (死亡原因多元性)

Manhon, Goldberg, & Washington, 1999; McEvoy, MacHale, & Tierney 2012)

What do we know about the issues

- Longer life expectancies of Persons with ID, a newly arisen challenge: higher chances to face bereavement of losing their parents
 - Mean age at death for people with ID was about 19 years in the 1930s and increased to 66 years in the 1990s (Coppus, 2013)

Impact of everyday stressors

Social, cultural, environmental and developmental factors can have significant impact on the expression of both psychiatric and behavioral disorders in older people with intellectual disabilities. Stressors may be multiple, and include separation from or bereavement as the result

of the death of a parent, other relative, or friend; loneliness; or sudden relocation. Though much remains to be clarified as to quantifying specific influences on age-related changes in persons with intellectual disabilities, the general consensus is that perceived symptoms need to be evaluated in a broader context, and not necessarily attributed to one individualized factor. They should be explored as part of a complex interaction of the individual with his or her environment.

WHO (2001)
ONG

What do we know about the issues

- There is evidence that suggests Persons with ID can understand death
 - Life and Death Education Programme can probably be offered to persons with ID
 - No related studies on Chinese

Concept of death and perceptions of bereavement in adults with intellectual disabilities

J. McEvoy,¹ R. MacHale² & E. Tierney³

¹ School of Health & Science, Dundalk Institute of Technology, Dundalk, County Louth, Ireland

² Department of Psychology, COPE Foundation, Cork, County Cork, Ireland

³ National Education, White, Bell, School, Carrigrohane, Ireland

Results Nearly one quarter of participants had a full understanding and over two-thirds a partial understanding of the concept of death. Death comprehension was positively correlated with cognitive



Exploring concepts of death of Persons with ID



Developing and evaluating death education model targeting on Persons with ID



Exploring bereavement reactions of Persons with ID and Develops assessment tool

Research...

Systematic investigation of service needs

Scientific evaluation of intervention and evidence-based practice



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Practitioners

Researchers

Product
(Research in service
setting)

Collaboration

Between

Research Team (Researcher) and
Service agency (Practitioners)

Skills & Knowledge

Practitioners(TWGHs)

Researchers (HKU)

- Knowledge on Persons with ID
- Experience on working with Persons with ID
-
-
- ...

- Knowledge on Life and death education, and bereavement
- Knowledge and skills on Research
-
-



**Life and Death Education
Study on Persons with ID**

Values & Cultures

Practitioners

- Direct experience
 - Clinical evidence
 - Service oriented
 - Client's benefits and rights
 - Client individualization and flexibility
-
-
- ...

Researchers

- Scientifically generated evidence
 - Logic and statistics
 - Systematic gathering of information
 - Consistency & guidelines
-
-

Roles & Responsibilities

Practitioners(TWGHs)

Researchers (HKU)

Project
Planning
Stage

- Clinical experience and observation

- Literature review
- Advise on research methodology

Data collection
Stage

- Participants Recruitment
- Protection of participants' rights

- Measurements/questionnaire design
- Development of intervention model

- Data collection
- Intervention implementation

Data Analysis
Stage

- Data Analysis

Project Overview

- Multi-stage and mixed research methods (4 phases) were adopted in order to reach multiple objectives.

Phase I study

Exploring concepts of death of Persons with ID

Phase II study

Evaluation of the effectiveness of a life & death education model on Persons with ID

Phase III & IV study

Development of 'Bereavement Reactions of Persons with Intellectual Disability Scale' (BBPID) (智障人士喪親行為量表)

Phase I Study

Exploring the concepts of death of Persons with ID

- Study design

- Quantitative, structured-questionnaire survey
- Cross-sectional



- Participants (N=112)

- Recruited by stratified random sampling in 16 TWGHs rehab service units
- Mild-moderate grade ID
- Participation consent from participants & their

Response
rate 67.9%

family

Measurements

Death concepts

Non-functionality

不能活動

Irreversibility

不能逆轉

Universality

廣泛性

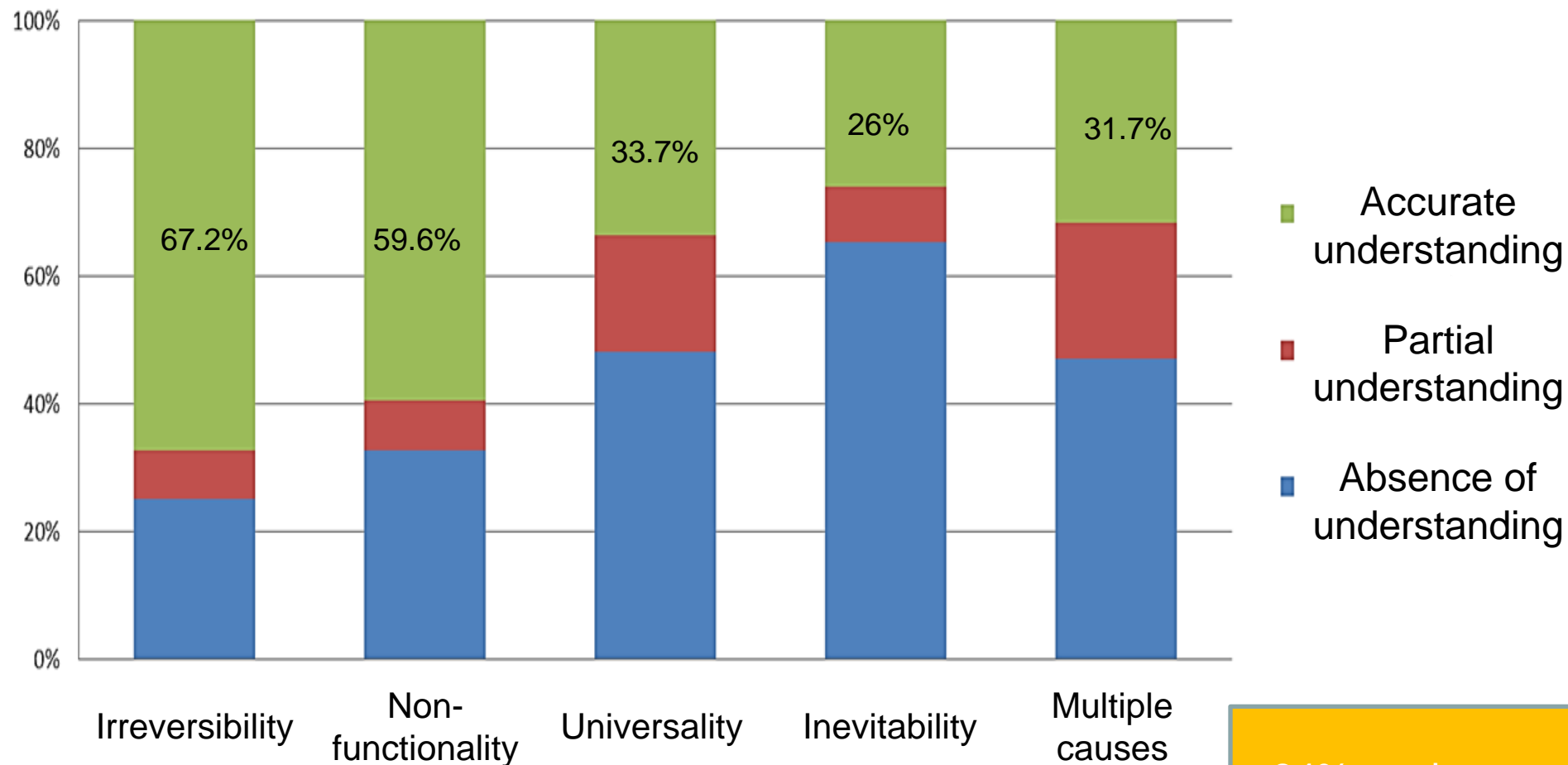
Inevitability

不能避免

**Multiple Causes of
Death** 多元因素

(McEvoy, MacHale, & Tierney, 2011)

Understanding on Death concepts (N=104)



84% moderate
ID; 16 % mild ID

Implications from Phase I Study

- At least one-fourth of the participants could understand death concepts to certain extent. **We can no longer deny them the need to grief because of their cognitive deficits.**
- Death is a **multi-dimensional concept**. Life and death education for Persons with ID should be built upon the multi-dimensional concept of death.

Phase II study – “Life-Bulb” Life and Death Education Programme for Persons with ID

生命電燈膽

Death- is like a ‘light bulb’ (Life bulb) that sheds light to our life.

When this **light bulb is gone**, we can barely see anything and conclude that there is nothing around us. We may presume death will not happen to us and take our lives for granted.

When the **light bulb is on**, we not only have a glimpse of death per se, we can also have better understanding about life (world around), treasure the previous relationships and find meaning in life.



To bring the experience of ‘through understanding death, appreciating the meaning of life’ to Persons with ID

Programme framework

Death concepts

Non-functionality

不能活動

Irreversibility

不能逆轉

Universality

廣泛性

Inevitability

不能避免

Multiple Causes of Death

多元因素

Corresponding Life concepts

- Growth, function, reproduction

- Meaning of life, unfinished business

- Relationship with others

- Relationship with self, death anxiety, advance care plan

- Facing loss, bereavement and grief

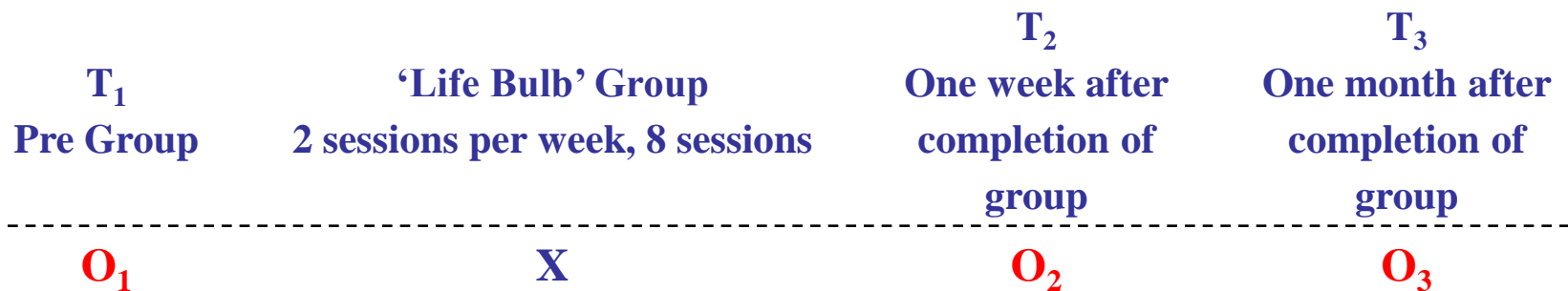
(McEvoy, MacHale, & Tierney, 2011)

- **Participants**

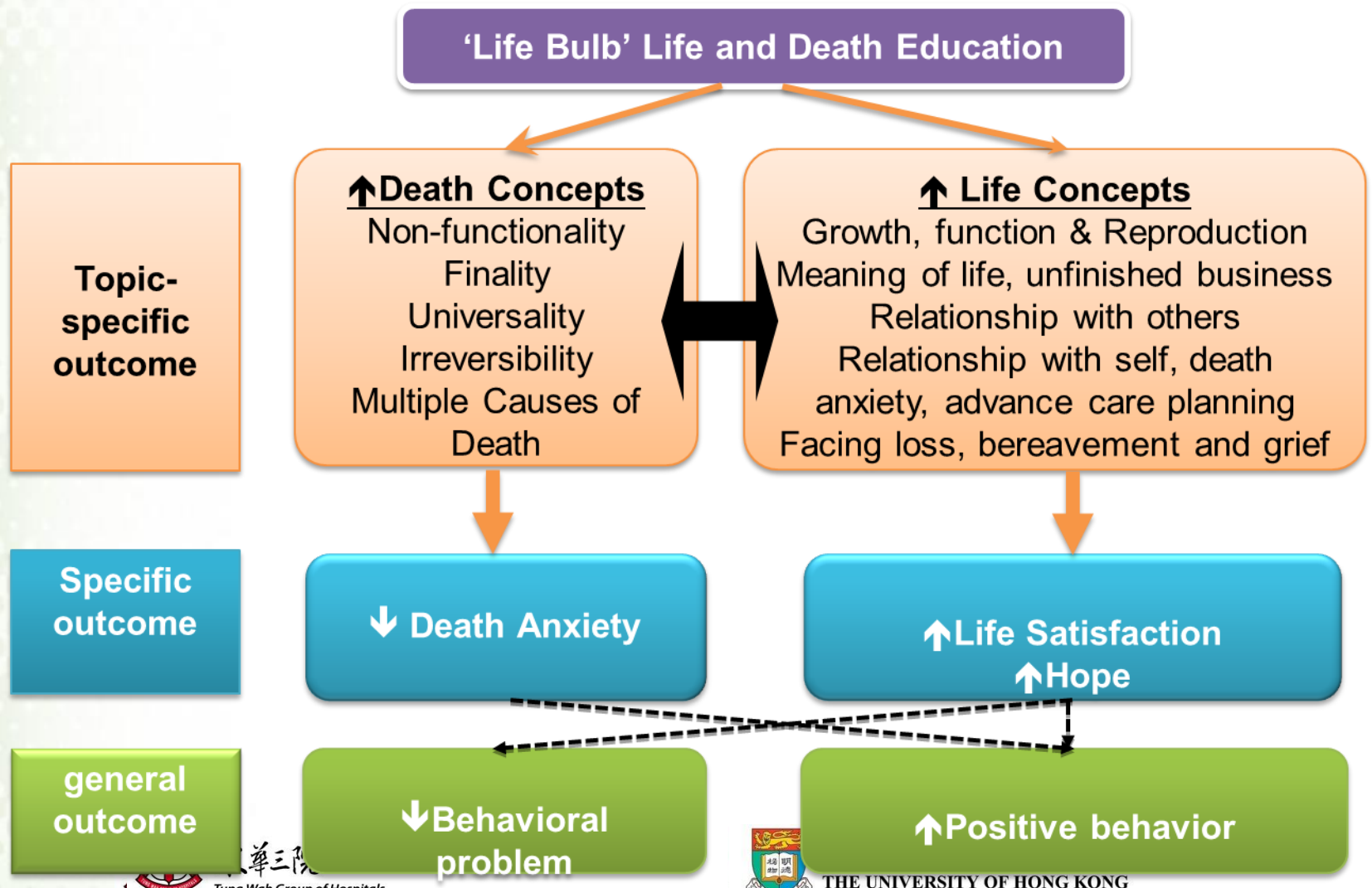
- 4 pilot groups were held in 4 rehab service units of TWGHs (N=22)
- Mild to moderate ID grade

- **Study Design**

- Quantitative research method and One-group pretest-posttest design



Evaluation framework



Implications from Phase II Study

- Most outcome indicators changed in expected directions. Particularly, results shown statistically significant **increased understanding on certain death and life concepts, lowered death anxiety and fewer behavioral problems**
- Life and death concepts **are teachable to Persons with ID**
- Implications on programme improvement: **strengthening experiential learning components on part of the programme and incorporate different means of teaching medias according to the communication ability of participants**

Phase III study

– Development of Assessment tool on Bereavement Reactions of Persons with ID (BBPID, 智障人士喪親行為量表)

- Study Design
 - Qualitative research method- Focus groups
- Participants
 - 35 caregivers of Persons with ID (TWGHs staff and family caregivers)



BBR-ID

An item pool with
28 items was
obtained from the
data analysis.
(only part of the
item list is shown)

智障人士喪親行為反應量表(BBR-ID)

- 以下句子描述另一些有關智障人士經歷親人密友離世後可能會有的行為表現(每句中的「親人」可包括親密朋友，如要好的院友)，請你根據受訪個案過去一個月的行為表現，評估受訪個案有幾經常有以下行為。由「從不」、「稍有」、「有時」、「經常」和「無時無刻」五個答案中選取你認為最能形容受訪個案的答案。

從不= 過去一個月內沒有出現過

稍有= 過去一個月內只出現一兩次

有時= 過去一個月內平均每星期一兩天有此行為

經常= 過去一個月內平均每星期數天有此行為

無時無刻= 過去一個月內幾乎每天都出現

| | 從不 | 稍有 | 有時 | 經常 | 無時無刻 |
|--|----|----|----|----|------|
| 抑鬱症狀 (6 items) | | | | | |
| 1.1) 對嗜好的興趣減少(anhedonia) | 0 | 1 | 2 | 3 | 4 |
| 1.2) 表現安靜，少說話(low energy/withdrawn/anhedonia) | 0 | 1 | 2 | 3 | 4 |
| 1.3) 不願進食(change of appetite) | 0 | 1 | 2 | 3 | 4 |
| 1.4) 晚上不願睡覺(change of sleep pattern: insomnia) | 0 | 1 | 2 | 3 | 4 |
| 1.5) 白天不願起床或睡太多(low energy/lethargy) | 0 | 1 | 2 | 3 | 4 |
| 1.6) 哭泣(sad mood/crying) | 0 | 1 | 2 | 3 | 4 |
| 焦慮症狀 (9 items) | | | | | |
| 1.7) 脾氣暴躁，亂發脾氣(agitation/irritability/anger/aggression) | 0 | 1 | 2 | 3 | 4 |
| 1.8) 咒罵他人(aggression/anger) | 0 | 1 | 2 | 3 | 4 |
| 1.9) 有躲起來的行為(例如「搵」落枱底、以衣服包起自己、獨個兒躲在角落等等) (avoidance behavior?) [can be withdrawn behavior due to depression too] | 0 | 1 | 2 | 3 | 4 |
| 1.10) 襲擊他人(例如咬人、打人) (anger/aggression) | 0 | 1 | 2 | 3 | 4 |
| 1.11) 不服從，難以被控制 (aggression? Not sure) | 0 | 1 | 2 | 3 | 4 |
| 1.12) 精力發洩的行為(例如：扔東西、把西東掃落地下、在床上跳、敲打物件等等) (agitation/restlessness/anger) | 0 | 1 | 2 | 3 | 4 |
| 1.13) 傷害自己(例如打自己、以身體使勁地撞其他物件等等) (self-injurious) | 0 | 1 | 2 | 3 | 4 |
| 1.14) 不適當地大叫或尖叫(irritability/agitation) | 0 | 1 | 2 | 3 | 4 |
| 1.15) 到處奔跑，不易停下來(restlessness/avoidance behavior/panic) | 0 | 1 | 2 | 3 | 4 |



Phase IV Study

– Validation Study on BBPID

- **Study Design**

- Quantitative, structured-questionnaire survey

- **Participant**

- Convenient sampling in TWGHs and other Service agencies
- 38 participants in G_E (PwID experienced loss of family members from death in past two years) & and 26 G_C (PwID without bereavement experience) respectively.

Criterion Validity: Concurrent Validity

「智障人士複雜哀傷反應量表」

Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID)

| | Whole scale | Traumatic grief subscale | Separation Distress subscale |
|-------|-------------|--------------------------|------------------------------|
| BBPID | .874** | .761** | .864** |

註. ** $p < .01$

Criterion Validity: Predictive Validity (Only part of the item list)

| Compare G_E and G_C difference on BBRID items | Mean (SD) | | <i>t</i> |
|---|----------------------------------|--------------------------------|-----------|
| | Experimental (G_E) (N=38) | Comparison (G_C) (N=26) | |
| 對逝世親人[在世親人]照片有反應 | .61 (.718) | .077 (.272) | -4.124*** |
| 晚上不願睡覺 | .13 (.343) | 0 (0.0) | -2.368* |
| 脾氣暴躁，亂發脾氣 | .61 (.974) | .65 (.745) | .215 |
| 對身邊不同人說有關親人逝世[在世親人]的事 | .45 (.686) | .46 (.948) | .069 |
| 逃避談及或想起逝世親人[在世親人]有關的事 | .16 (.369) | .04 (.196) | -1.774 |
| 對他人不理睬，像心不在焉，若有所思的 | .32 (.619) | .15 (.368) | -1.309 |
| 重覆地說着有關死亡的說話 | .29 (.611) | 0 (0.0) | -2.920** |
| 不服從，難以被控制 | .29 (.611) | .31 (.471) | .128 |
| 咒罵他人 | .32 (.662) | .42 (.578) | .680 |
| 精力發洩的行為 | .24 (.589) | .12 (.326) | -.954 |

註. * $p < .05$; ** $p < .01$; *** $p < .001$; []內文字為比較組量表版本的用字(words in [] used in comparison group)

Implications from Phase III & IV Studies

- The items derived were consistent with findings from literature.
- Observable items by proxy, user-friendly
- Despite small sample size, the results provide preliminary support for the validity of the BBPID and some items are able to differentiate between bereaved PwIDs and non-bereaved PwIDs

Challenges in Collaboration

Project Planning Stage

- Research ethical concerns in research on Persons with ID
- Measurement choices and questionnaire design

Implementation Stage

- Recruitment difficulty and possible drop outs
- Timeline concern
- Arrangement of data collection (Appropriate assessor, multiple-rater, time & venue)

Data Management Stage

- Involvement of Service unit staff in data input and training
- Unexpected results from data

Administration

- Change of Project staff



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研究結果

- 智障人士可以理解死亡。
- 我們再不能以智障人士不理解死亡而否定他們面對死亡或喪親經歷而產生的需要。



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《研究之後》 智障人士及家人 面對生死課題的需要



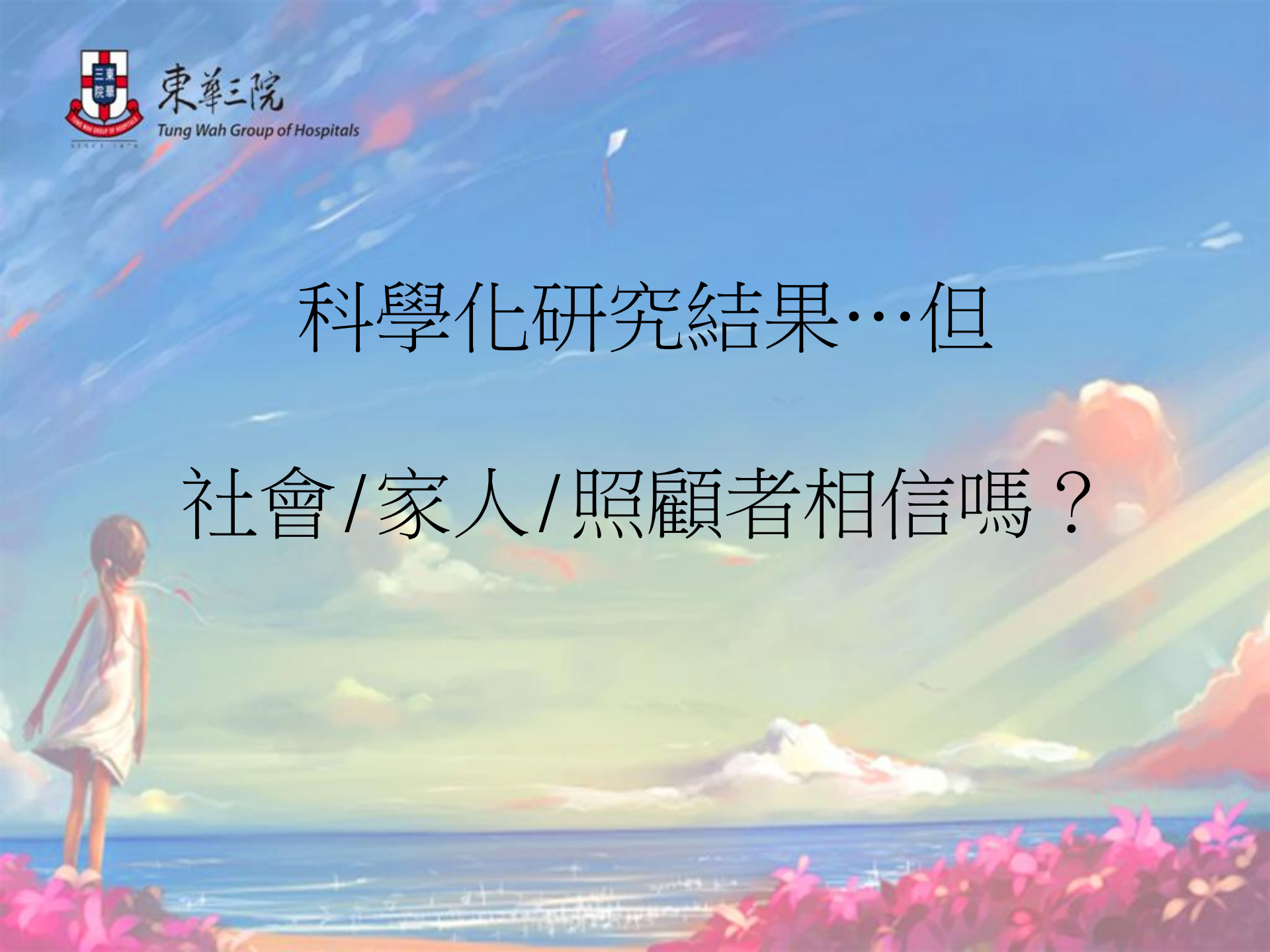


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科學化研究結果…但

社會/家人/照顧者相信嗎？





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一樣米養百樣人

- 每個人的差異
- 智障人士亦一樣





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- 不懂表達不等於不懂
- 不懂不等於不能學懂





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研究結果，引申的需要





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給智障人士/家人/照顧者 提供生死教育



花草



金魚



人生



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- 我們要與他們談關於死亡的事





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他們需要生死教育，
但我們有多少人接受過生死教育？





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- 我們有否假定自己
對於死亡的認知
一定會較患智障的人士多和正確？
- 例如：





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不能活動的概念





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不能避免的概念





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- 發展為智障人士提供生死教育的方法





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當智障人士面對死亡

- 如何照顧他們的情感需要及意願？





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- 給他/她學習或表達關心親人的機會





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智障人士哀傷輔導服務發展





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尊重

- 業界一直倡議不要把智障人士視作孩子看待
- 更希望把他們視為家庭真正的一份子





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家人/照顧者/社會 對智障人士「另眼相看」

- 是否固守/定形在智障人士早期被評定的智障程度？





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我們一向相信他們有學習能力

- 但有否包括他們對生死的認知與感受？



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謝謝大家

