The Point of View of the Professionals Working with Policymakers, Patients and Families

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MENTAL HEALTH
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Faculty Disclosure

X	No, nothing to disclose
	Yes, please specify:

Company Name	*Honoraria/ Expenses*	*Consulting/ Advisory Board*	*Funded Research*	*Royalties/ Patent*	*Stock Options*	*Ownership/ Equity Position*	*Employee*	*Other (please specify)*

Agenda

- Mental ill-health
  - Access to care, respect and dignity
- Assessing quality of life
- Partnerships for improving mental health
- Project on best practices for service users, carers and practitioners working together

Mental Ill-Health, Access to care, Respect and Dignity Worldwide

- Service users and carers have the regular experience of stigma and discrimination in the community, poor access to care for mental and physical health problems, and treatment under conditions that rob them of respect and dignity

Partners in Mental Health Care

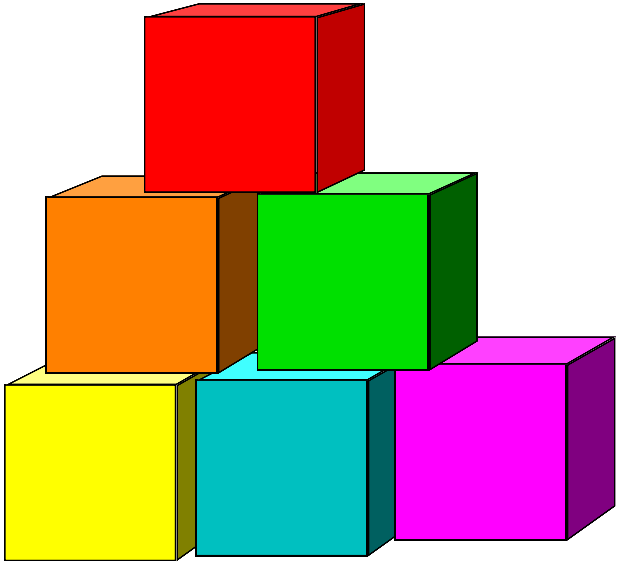
- Service users
- Families and other informal carers (‘Carers’)
- Doctors and health professionals
- Policymakers, Government agencies, Community leaders and traditional healers, Health care industry

Partners in Mental Health Care

- Service users and their families have important roles in quality of mental health care
- Service users and carers are involved in a range of activities
  - Care, social inclusion, self-help projects
  - Research
  - Advocacy
  - Policy development, service planning
- Discerning will and preferences cf best interests, and facilitating supported decision- making

Defining Quality of Life - QOL

- Unitary concept - life satisfaction, happiness, wellbeing *vs* several domains (and changes gradually)
- Generic / specific
- 'Subjective' / 'objective'
- Profile / index



Quality of Life - QOL

- An individual’s perception of his or her position in life
- in the context of the culture and value systems in which he/she lives
- in relation to his/her goals, expectations, standards and concerns

Sartorius

Culture and QOL

- World Health Organization Quality of Life Assessment - WHOQOL
- Developed simultaneously in 15 countries, available now in more
- Developed by experts and
- Contributions from lay people, patients, clinicians (focus groups)

WHO Quality of Life Assessment - WHOQOL

- People in varying conditions and circumstances, and across cultures

WHOQOL

- Subjective, ‘generic’
- Profile of scores - 4 domains
- *Physical, Psychological, Social Relationships, Environment*
- *WHOQOL 100, WHOQOL 26, WHOQOL 8*

WHOQOL-Bref domains

1. Physical
   - Activities of daily living
   - Pain & discomfort
   - Dependence on medicinal substances
2. Psychological
   - Self esteem
   - Positive/negative feelings
   - Thinking, learning & concentration
   - Spirituality
3. Social relationships
   - Personal relationships
   - Social support
   - Sexual activity
4. Environmental
   - Financial resources
   - Freedom
   - Physical safety
   - Health
   - Home environment

Assessing QOL

Attitudes, perceptions and expectations

mediate the way that abilities, opportunities, level of independence, quality of the environment affect a person's QOL

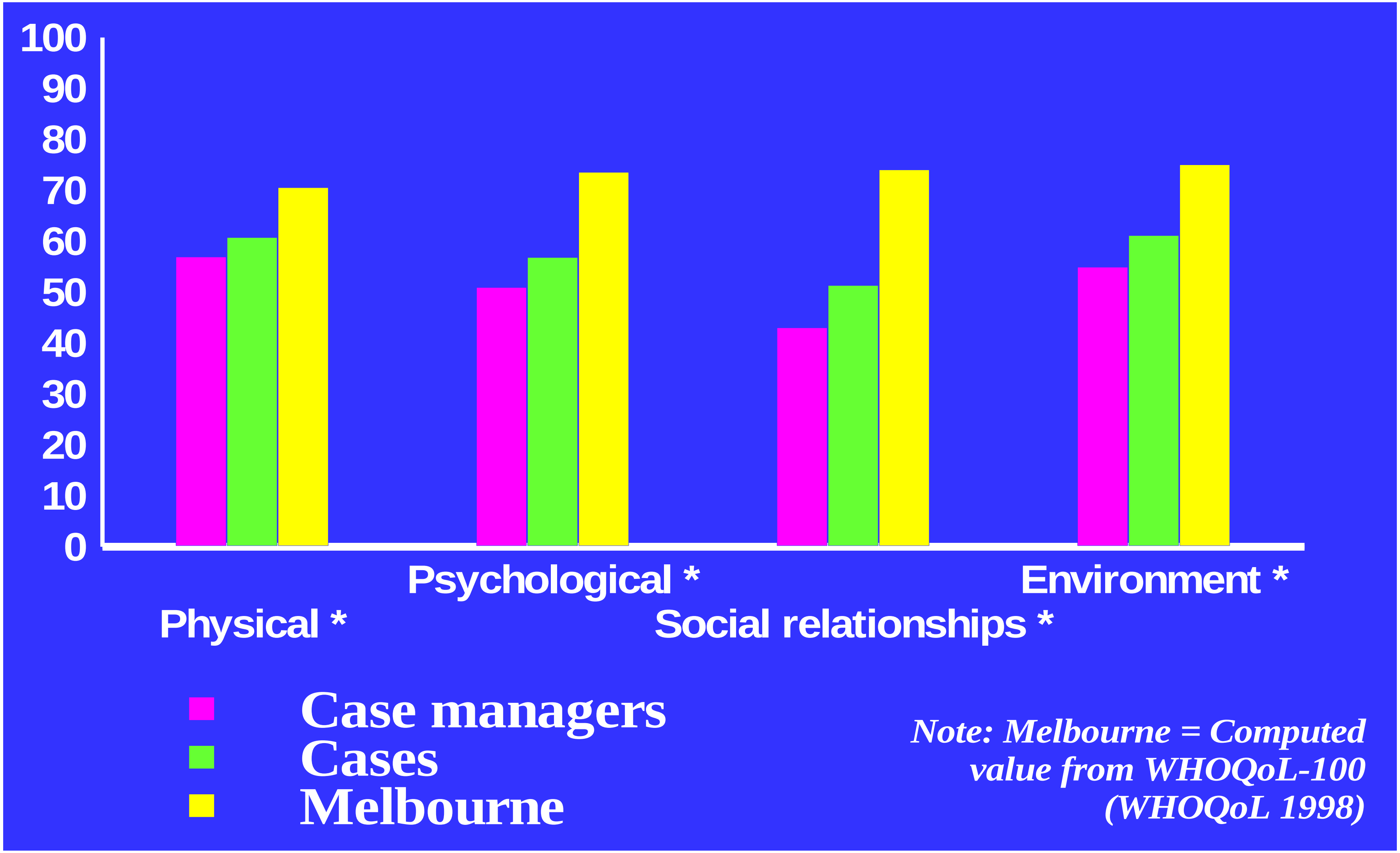
Adjustable internal standards

"We health professionals often make inaccurate value judgements about patients' QOL on the basis of, for example, a 'poor' home environment"

Assessment of the Quality of Life of People with Long Term Psychosis

- To investigate the feasibility and usefulness of the WHOQOL Bref for assessing the subjective quality of life of people receiving long term treatment for psychosis
    - Herrman HE**,** Hawthorne G, Thomas R. 2002. Quality of life assessment in people living with psychosis. Social Psychiatry and Psychiatric Epidemiology 37:510-518

WHOQoL Bref domain scores



Note: Melbourne = Computed value from WHOQoL-100 (WHOQoL 1998)

* = Cases vs managers, t-test, p < 0.01

Case managers vs. cases: WHOQoL

R = 0.31

Partners in Mental Health Care

- Efforts to improve mental health care through partnerships and positive community attitudes
  - Resolutions and guidelines in several countries
  - But their wide use and structural changes to support them are yet to be achieved

WHO Minimum Actions Required for MH Care

10 Recommendations, World Health Report 2001

- Recommendation 5*: Involve communities, families and consumers*
- Low level of resources
  - Support the formation of self-help groups
  - Fund schemes for NGOs & mental health initiatives
- Medium level of resources
  - Ensure representation of communities, families, and consumers in services and policymaking
- High level of resources
  - Foster advocacy initiatives

WPA Project on Partnerships with Service Users and Carers, 2008-11

- WPA invited service users and family carers to join in its work as members of a taskforce
  - Recognising their essential contribution to improving mental health in any country
  - Recognising their needs
- The taskforce has prepared recommendations for the international mental health community on best practices in working with service users and carers

World Psychiatric Association (WPA) Project on Best Practices in Working with Service Users and Families: *Aims*

- Prepare recommendations for best practice in working with users and carers, for the international mental health community
- Each country needs specific guidelines to apply these recommendations
- People can help each other internationally with recognising the different ways in each country and district

WPA Project on Best Practices in Working with Service Users and Families: *Audience*

- The member societies of WPA in 117 countries and psychiatrists worldwide
- A wider audience including employers, schools, community leaders and service users and carers themselves – to encourage and assist their work with local professional groups

10 Recommendations

- (1) Respecting human rights is the basis of successful partnerships for mental health
- (2) Legislation, policy and clinical practice relevant to the lives and care of people with mental disorders need to be developed in collaboration with users and carers

10 Recommendations

- (6) The best clinical care of any person in acute or rehabilitation situations is done in collaboration between the user, the carers and the clinicians
- (7) Education, research and quality improvement in mental health care also require this collaboration

10 Recommendations

- (9) WPA member societies and other professional groups should collaborate with users' organisations, carers' organisations and other community organisations to lobby governments for political will and action for better funding of services, community education and fighting stigma

10 Recommendations

- (10) Enhancing user and carer empowerment includes the development of self-help groups; participation in service planning and management boards; employment of people with mental health disabilities in mental health service provision; and the creation of inclusive local anti-stigma programs

WPA RECOMMENDATIONS

Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers

Jan Wallcraft[1], Michaela Amering[2], Julian Freidin[3], Bhargavi Davar[4], Diane Froggatt[5], Hussain Jafri[6], Afzal Javed[7], Sylvester Katontoka[8], Shoba Raja[9], Solomon Rataemane[10], Sigrid Steffen[11], Sam Tyano[12], Christopher Underhill[9], Henrik Wahlberg[13], Richard Warner[14], Helen Herrman[15]

(World Psychiatry 2011;10:00-00)

Conclusions

- Role of the professions in establishing partnerships
- Learning from experience and listening to all involved
- Expanding ethical standards for psychiatric practice
- Developing new projects