

Quality of life as a basis for system change

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Abstract: This paper celebrates Peter Huxley's contribution to placing quality of life at the centre of service planning and responses. Drawing on our research findings with 81 patients from Community Mental Health Teams, this paper argues that patient outcomes are improved when their voices are used to inform service design. Using the Manchester Short Assessment Quality of Life (MANSA), patients prioritised three of the eight domains: employment, financial stability and leisure activities. These findings were used to inform system change by addressing patient needs to increase their financial and social inclusion. This paper seeks to demonstrate the continued relevance of Peter's work with reference to two examples: mental health needs arising from COVID-19 and the needs of criminally exploited children and young people. It concludes that Peter's legacy provides the tools needed to ensure that services work together efficiently and effectively to address unmet needs and enhance quality of life.

Keywords: quality of life; system change; mental health; person centred; extra-familial harm

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Introduction

Long before the Social Services Well-being (Wales) Act 2014 and the Well-being of Future Generations (Wales) Act 2015, Peter's work was emphasising the significance of quality of life and emphasising the multi-faceted nature of this construct. In doing so, Peter placed the patient voice at the centre of service planning and responses. Rather than passive recipients, Peter's work has focused attention on the experiences of the individual and their perspectives regarding their ability to function in daily living, interact socially, and gain and retain employment (Schneider, Carpenter, Wooff, Brandon and McNiven, 2002). His work has been underpinned by the right for people to have their voices heard and the need to develop solutions based on their lived experience of the issues they face. Hence, Peter's work around social inclusion is based upon the tenet that individuals should have the ability and opportunity to participate in the key functions of society (Huxley, et al., 2012). This includes the opportunity to interact with the community, family members, access to employment, services, and the financial resource and social capital to do so. Hence, Peter's work has acknowledged the significance and interrelatedness of subjective and objective quality of life domains.

The relationship between quality of life and patient outcomes

My work with Peter has mostly been based on the Manchester Short Assessment Quality of Life (MANSA) which he developed with colleagues (Priebe et al., 1999). This instrument assesses quality of life in eight life domains (e.g. work and education, finances, health, family and social life, leisure, accommodation) and life in general, using the seven-point delighted – terrible scale (Andrews and Withey, 1976). The MANSA has been endorsed by the National Institute for Health Research and the Royal College of Psychiatrists (cited by Huxley et al., 2018). It has been used extensively and has been rated highly by participants. This is not surprising given that it captures a '...comprehensive and balanced audit of a person's life that goes beyond a disease model of mental health problems' (Schneider et al., 2002, p.423). Our findings from 81 patients in Community Mental Health Teams (Evans, Huxley, Maxwell and Huxley, 2014) highlighted the extent to which outcomes were improved when mental health services were designed to address patient quality of life. In our study, we used the MANSA to determine what mattered to patients, what they wanted from the service, and what responses added value to their lives. From this data, we were able to

advise the teams about what actions were needed and how outcomes could be improved. Our findings revealed that employment, financial stability and access to leisure activities were priority areas for patients. Patient perspectives were then used to develop greater partnership working across services with work centred around promoting awareness and opportunities for employment and developing work-based projects and supporting patients to access leisure activities through peer support. As such, our findings placed the onus on patient informed service design to improve patient outcomes.

Peter's work continues to have much significance, especially in light of the COVID-19 pandemic. In addition to the obvious health effects, COVID-19 has negatively affected mental health. This has primarily been associated with the impact of lockdown measures, where increasing numbers of the population have found themselves living in poverty, furloughed and confined to their homes. At one extreme, many people have found themselves caught within 'the pressure cooker of family life' (Green, 2020), while some have spent many months home alone with limited access to social contact. The pandemic has served to exacerbate pre-existing social exclusion for certain groups, such as those with significant mental illness (Huxley and Thornicroft, 2003). In short, COVID-19 has brought considerations about quality of life to the fore. Peter's legacy provides the pathway for collaborative responses between social care and mental health. His work provides for the comprehensive assessment of the objective and subjective quality of life so that interventions can be tailored to the unmet needs of the general population as well as vulnerable groups. Prior to the pandemic, findings from a literature review of general population studies of quality of life revealed that while the general population's satisfaction scores tended to be higher in family and lowest in finances, there were direct and indirect links emerging between events and satisfaction in the relevant domain (Evans and Huxley, 2002). Hence, change in one or more life domains is associated with dissatisfaction in that domain and overall quality of life. Conversely, making positive changes in domains with lower satisfaction ratings can lead to an overall improvement in quality of life (Huxley and Thornicroft, 2003).

The relationship between quality of life and system design

As social care and mental health services struggle with an increased workload following the pandemic, Peter's work provides the tools needed to ensure that services work together efficiently and effectively to address unmet needs. This has direct relevance to my work on improving service responses to criminally

exploited children and young people. Interventions tailored to young people's unmet needs are associated with higher levels of engagement, including those with previously low levels of engagement with services (Maxwell et al., 2022). Yet, we are still seeing many young people directed to existing services that were not designed to address the need of adolescents and extra-familial harm (Maxwell et al., 2019). Going forward, increased attention is needed on capturing young people's perspectives regarding what matters to them, their priorities and living conditions as well as their opportunities and ability to address their unmet needs (Evans et al., 2007). Rather than fitting vulnerable young people into a system that was not designed to respond to extra-familial harm (Maxwell et al., 2019) Peter's work continues to demonstrate the importance of understanding the influence of a wide range of factors relating to the quality of life. Identifying and protecting young people from criminal exploitation will only be successful if their unmet needs around housing, finance, employment, safety, living conditions, health, leisure, social capital and family relationships are addressed. Moreover, young people's capital and control over these factors are crucial determinants in reducing their vulnerability to criminal exploitation and heightening their ability to escape exploitative relationships. For this reason, Peter's work continues to have relevance to service design across social care. There is still much to do in embedding system change based on what matters to people and how services can work together to improve the quality of life for individuals across all its domains.

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