

CONFERENCE ABSTRACT

Thoughts and feelings about quality of care and support: the perspective of relatives of people with visual and intellectual disabilities.

ICIC20 Virtual Conference – September 2020

Paula Sterkenburg; Francis ter horst-lotterman¹

1: Vrije Universiteit Amsterdam, Amsterdam, Netherlands

Introduction

In the care for people with intellectual disabilities in the Netherlands there is a growing emphasis on the importance of the relationship with relatives and their involvement in care. They may be an important voice with regard to the uniqueness and life history of a person with intellectual disabilities, and subsequently concerning aspects needed to provide a high quality of care and life. However, commonly used models on quality of life and quality of care have been developed by researchers and/or care professionals. In this study, we aimed to explore the relatives' view regarding the quality of care and support for people with visual and intellectual disabilities (VID) and whether these views are linked to concepts of quality of life (e.g., of Schalock & Verdugo) and quality of care (e.g., of Donabedian).

Methods

We performed twelve semi-structural, in-depth interviews with relatives of people with VID living in a group-homes of a specialized care organization. We made use of visual representations and the laddering technique to elicit respondents' metaphors, constructs and emotions associated with quality of care and support.

Results

Analysis revealed seven overarching aspects of high quality of care and support based on the visual representations and stories of relatives: 1) 'Know' the person with VID; 2) Be partners in care; 3) Provide support from the heart; 4) Provide safety for the person with VID; 5) Provide a 'home' for the person with VID; 6) Provide opportunities for development; and 7) Continuity in care is a basis.

Discussion

There are clear linkages between the views of relatives of people with ID and concepts of quality of care and quality of life. These concepts seem closely connected and are intertwined present in the relatives' thoughts and feelings. The relatives' view on partnership between care professionals and relatives is based on the level of mutual trust

and is most visible at key moments when good care and support is either present or lacking.

Conclusion

Involvement in the provided care and support is important for relatives of people with VID and deserves special attention from care organizations and professionals.

Lessons learned

Relatives are important people in the life of people with VID with an unique perspective on good care and support, which may be essential for care professionals to capture in order to provide the best possible care and attain the highest possible quality of life.

Limitations

These results are limited to a specific population of people with VID. We do not know whether it can be generalized to, for example, people with VID living with less support in the community or people with other comorbid disabilities.

Suggestions for future research

We suggest a comprehensive comparative study of the perceptions of important care professionals, people with VID and their relatives about high quality of care and support.