CONFERENCE ABSTRACT

The outcomes of pilot projects of integrated home care in Lithuania from the informal carers' viewpoint

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Before the first IHC services were implemented, formal care at home was not part of Lithuanian culture. Most professionals and ordinary citizens alike had no concept or language for this way of caring. Most carers were women, and a high proportion of them had serious medical and social problems that were being neglected in order to provide care to relatives with serious chronic conditions. Many of the carers' conditions were extremely distressing. To address this situation, Integrated home care pilot projects were begun in 21 Lithuanian municipalities in 2012. IHC mobile teams consisted of social workers, nurses, their assistants, and kinesiotherapists. The major aim of the teams was to suppport family members who had the entire responsibility to care for relatives with chronic conditions. The organizers and service providers constructed the pilot projects in a way that fit in the local context. Rural and urban areas varied in how access to clients and development of human resources were organized. The realities of everyday life and current events in the community were taken into account. The informal carers were actively involved in the IHC service provision.

Aim: Given the major cultural innnovation that IHC constituted and the emphasis on the experience of the carers, the aim of the study was to analyze the implementation and outcomes of integrated home care pilot projects from the informal carers' viewpoint.

Methods: In home interviews with 14 carers were conducted using both structured and open ended stimulus questions and topics. Twelve focused discussion groups were conducted with team members, and the content on their observations and perceptions of the carers experiences were also analyzed. Together, these data were classified, compared, and conceptualized in order to express the variety of experiences of these participants.

Results: The informal carers described their situation before the project in almost all cases as very unsatisfactory and constantly worsening. Isolation, declining empathy, and physical deterioration were common and were expressed intensely. The informal carers spoke of IHC services with honeymoon enthusiasm. The carers appreciated the good quality service for a

reasonable price, and service integration. Burnout was reduced by decreasing physical overload and providing possibilities for respite. Cooperative work increased the quality of nurses' and carers' knowledge and skills, especially concerning bedsores. IHC mediation between carers and patients was new and was valued. Two of the major tasks that teams encountered were clarifying what the service could offer and gaining the trust of carers. Challenges with the new service included different understandings of hygiene, and getting used to many people visiting. Both groups recognized and valued the drastic new experience of partnership in care.

Conclusions: The informal carers were positive about the IHC teams and their work. The service of IHC helped the families to combine family and work commitments, prevented burnout, and strengthened their self-care skills. Services of counseling about care at home were started. These findings from carers and staff proved to be essential in the establishment of IHC as a nationwide form of care.