“Pedogeriatrics”: a pediatric nephrologist’s outlook on common challenges facing pediatric and geriatric nephrologists

Jose Grünberg

Abstract  Dramatic demographic changes longevity and medical progress helped create a new population made up of the survivors of previously fatal diseases. These trends pose new major social and economic challenges that should be accounted for in health policy making. This paper discusses the similarities between the specialties of pediatrics and geriatrics, especially in the realm of patient care. Children and the elderly share a limited autonomy and dependence on the human environment (i.e., willing and able caregiving persons) due to age or disease. The long-term care of dependent patients (DP) requires caregiving persons who share with dependent persons the risk of losing autonomy, facing burnout, family disruption, and interference with work and educational activities. Families with DPs may face potential losses of income because both patients and caregivers are partially or completely unable to work, the former for medical reasons and the latter due to the new demands on their time and energy. Additionally, new expenses have to be met because while direct medical expenses might be covered by insurance or the State, other expenses have to be financed by the family, such as co-payments for medicines, new water or electricity home installations, and transport and eventual hotel costs if they have to stay overnight near a hospital outside of their town. The main objectives of long-term care should be to maximize patients’ independence and prevent their physical and psychological deterioration while minimizing the social, economic and personal costs to caregivers. To achieve these goals, one needs a holistic approach, a multidisciplinary professional team (doctors, nurses, social workers, nutritionists and psychologists) and auxiliary staff (secretaries, electricians, administrators, messengers, cleaning staff, doormen, nursing aids and coordinators of medical appointments and medical procedures). Optimal management of DPs on chronic treatments such as chronic dialysis requires adequate communication skills, respectful attitudes toward patients and caregivers and effective use of communication and information technologies. Auxiliary personnel require specific training to contribute effectively to the DP attention processes. This paper postulates that pediatric and geriatric teams and their patients would benefit from closer training and sharing of experiences and systems.

Keywords  Pediatric nephrology · Geriatrics · Caregiver · Pedogeriatrics · Peritoneal dialysis

Introduction

A worldwide increase in aging population, both healthy persons and those with chronic diseases, poses
new challenges to medical practice. We are faced with
an increasing number of long-term-care patients with
limited autonomy, dependent on the human environ-
ment (i.e., willing and able caregiving persons) and
who suffer from a wide spectrum of potential illnesses
and disabilities. Patients on renal replacement therapy
(RRT) are exposed to complications arising from the
disease itself or from RRT (e.g., severe infections,
osteodystrophy) and intercurrent diseases (e.g., myocar-
dial infarction, malignancies, psychological depression).

Many characteristics of elderly patients, especially
if they have chronic illnesses, are similar to those of
healthy young children. Since newborns and infants
have an extreme lack of autonomy and maximum
dependence on others, pediatricians must master the
skills, training and attitudes needed to deal with such
dependent patients. Thus, I postulate that the experi-
ence of pediatric nephrologists should be useful for
geriatric nephrologists since their patients share the
conditions of limited autonomy and major dependence.

My experience in a twinned adult and pediatric
chronic peritoneal dialysis (CPD) service has helped
me appreciate the challenges faced by patients,
children and adults alike, who lack autonomy and
are highly dependent on others. I also became aware
of the deleterious effects this dependence may have
on family members and other caregivers.

Both services, adult and pediatric, share staff and
facilities (nurses, social workers, administrators, sec-
retaries, consulting room, hospitalization facilities and
computerized medical records). Between 1998 and
2008, 301 patients were on CPD in our adult unit, 238
(79%) and 46 (15%) were aged over 65 and 70 years,
respectively, at the start of CPD. Our 20 years’
pediatric CPD experience on 59 patients has been
reported elsewhere [1].

The aim of this editorial is to discuss the similarities
and dissimilarities of the care process in the extremes
of life, with special emphasis on patients with RRT on
CPD. Based on this discussion, this paper postulates
that pediatric and geriatric teams and their patients
would benefit from closer training and sharing of
experiences and systems.

**Pedogeriatrics: a historical outlook**

Geriatrics pioneers emphasized the similarities
between pediatrics and geriatrics, such as patients’
loss or lack of autonomy and their dependence on the
human environment. In 1909, Nascher [2], inspired
by pediatrics, coined the term *geriatrics*, to cover the
same field in old age that is covered by the term
*pediatrics* in childhood.

“As interest in the dependent child led to the
scientific study of child welfare,” reasoned Nascher,
“so might an interest in the dependent aged lead to
the scientific study of senility, of the needs and wants,
the peculiarities and infirmities, the happiness and
welfare of the aged.” In the introduction to the book
*Geriatrics*, Abraham Jacobi, the father of American
pediatrics, said “The world is entitled to demand of
every one of us a complete knowledge and profound
interest in the physical life both of the young and the
old” [3–6].

The heading of the Geriatrics section dedicated to
Nascher in the Medical Review of Reviews noted
“Pediatrics must be supplemented by Geriatrics” [3].

**Similar factors affecting the care of children
and elderly persons with a chronic illness**

Pediatricians and adult healthcare providers are
strongly involved in their patients’ diagnosis, treat-
ment and choice of RRT. Long-term medical care
involves (a) a wide spectrum of people as caregivers,
(b) the effective use of modern communication and
information technologies and (c) adequately trained
health care professional and auxiliary staff (secretar-
ies, electricians, administrators, messengers, cleaning
staff, doormen, nursing aids and coordinators of
medical appointments and medical procedures).
Long-term care calls for months, years or even
decades of caring for loved ones. Burnout and
exhaustion are frequent. Both care-recipients and
caregivers face loss of autonomy, interdependence,
financial costs and further disease or handicaps [7, 8].

The approach to these new challenges needs to be
focused on the family, since they are the most
directly affected by the demands for assistance from
the DP and they are expected by most societies’
norms and values (sometimes even on a legal basis)
to provide and/or finance such long-term care. It is
important to note that there are no rigid borders
between caregivers and care-recipients, since both
roles might be fulfilled either successively or simul-
taneously as the following cases illustrate [7, 9].
Case 1 Lucia, a 7-year-old girl on automated chronic peritoneal dialysis (APD), lived with her mother, grandmother and two great-aunts. The four adults were Lucia’s caregivers. Her father had emigrated and no longer participated in family life. Then, one of her great-aunts underwent a leg amputation due to vasculitis and thus also required care. The family now had two care-recipients who were highly demanding. Lucia, despite her young age, also became both a caregiver and care recipient. Lucia’s mother was forced to change jobs to devote more time to caregiving.

Case 2 Juana H., a 77-year-old woman with a familial renal disease started continuous ambulatory peritoneal dialysis (CAPD) in December 2004. She could care for herself as she was highly skilled and trained in the CAPD technique, after having provided long-term care to a daughter and a son, Silvia and Raul. Raul had started CAPD in May 1991 at the age of 47, and after 2 years on CAPD, he was transferred to hemodialysis. Silvia, after 10 years on CAPD, underwent a successful renal transplantation in October 2003. Thereafter, she shared with her mother the care of her brother.

These are some examples of the dynamics of the long-term care process with its unpredictable challenges such as the unavoidable turnover of caregivers and role changes between caregivers and care-recipients. Caregivers may quit their roles as a result of different factors: family disruption, exhaustion and burnout, diseases or merely the desire to lead a quieter life [10]. The human and economic resources for caregiving are not only limited, but also extremely dynamic. Caregivers themselves must be protected so as to prevent their burnout. Our experience in this aspect has been frequently very unfortunate: fathers abandon their sick children leaving mothers as the main caregiver. Adult family members abandon their elderly, dependent parents, leaving institutions and society in general to take care of them [7].

Children and family members who are not directly involved in the caregiving are not exempt from strong changes such as disruption of normal family activities, changes in economic status, the patient moving to or out of a nursing home, hospitalization requirements or switching between the two major dialytic modalities [9]. All these entail potential dramatic crises and call for a critical re-planning of all aspects of the care process. The switch from in-center hemodialysis to home peritoneal dialysis involves structural changes in the home: for example, the need for room for devices, bags and cyclers that may lead to losses of individual room space for some or all members of the family. The provision of an adequate electric and water supply is another challenge for low-income families, which is not usually covered by governmental chronic dialysis funding.

The importance of auxiliary health care staff

Health care is delivered within a closely interconnected network made up of health care professional staff (i.e., doctors, nurses, psychologists, social workers and nutritionists among others), patients, caregivers and auxiliary staff. However, the auxiliary staff often is neglected in the planning processes although they play a major role in delivering support and services to patients and caregivers. Phone operators, electricians, administrators, messengers, cleaning staff, doormen, nursing aids, coordinators of medical appointments and medical procedures are in close contact with patients and caregivers. Phone operators, electricians, administrators, messengers, cleaning staff, doormen, nursing aids, coordinators of medical appointments and medical procedures are in close contact with patients and caregivers. 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Auxiliary staff has more opportunities and more time to talk to patients and offer them emotional support. They may simply lend an ear to their problems, concerns, doubts and complaints. State-of-the-art medical technology may fail if auxiliary staff do not have specific training and if they cannot appreciate the importance of such details as inappropriate scheduling of appointments, failure to take into account the occupations and social life of patients and their educational or leisure activities. Adequately trained auxiliary staff provides effective coordination of medical appointments and medical procedures with public transportation schedules or caregivers’ occupation and time schedules [11].
**Communication between health care staff and patients. The potential and the reality**

The long-term care of patients requires effective communication. E-mails, phones (both fixed and mobile) and short message service (SMS) are relatively accessible even for poor people in developing countries. Even the poorest of our patients have access to mobile phones. Paradoxically, this improvement in terms of communication may lead people to exasperation and exhaustion from a stream of recorded phone messages and reiterative reference to previous messages. Patients and their families must have continuous access to a person who has adequate knowledge of the patient and can answer e-mails, phone calls or SMS in real time [12]. This resource is extremely important for the prompt treatment of complications, the coordination of procedures and appointments, or even merely to comfort and reassure the patients and their families.

Staff members must master communication skills with patients both person-to-person and through communication technologies. Ineffective communication with patients and their families often leads to noncompliance [13]. On the other hand, too much unplanned information often overwhelms the capacity of patients to understand prescriptions. It is important to minimize the need for patients to travel to receive information, advice or services that could be delivered through communication technologies. If travel is inevitable, schedules should take into account the patient’s logistics such as travel time, bus or train hours and the cost of staying overnight in the city where the hospital is located [12].

All staff members need to be trained in the effective, efficient and proper use of communication technologies and be able to detect and avoid malpractice or abuse (for example, spamming patients with advertising or information of little relevance, failing to reply to patients’ e-mails, phone calls or answering in rude or noninformative ways). They also need to train patients and their families on the effective use of the communication technologies that will be used for patient–staff exchanges. Good communication between patients and caregivers, nursing staff and the renal team is crucial in improving confidence and compliance [13, 14].

**Respect for care-recipients. Social attitudes toward dependent people**

The caregiver must show respect for people in adverse situations. Certain attitudes and language may unintentionally lead us to treat patients in a humiliating or degrading way [7]. For instance, seniors who are sick or handicapped continue to be seniors, and residents and nurses must show them the same respect as they would show to other adults.

Medical staff may address adolescents and old people in a patronizing way, using words like “sweetie”, “dear”, “love” or being inappropriately familiar by addressing the elderly by the first name, instead of using Mr., Mrs. or Miss.

Frequently, doctors and nurses leave out of the conversation children or elderly persons, who are capable of participating in normal verbal communication, even when discussing matters that are directly related to their care.

I learned an important lesson from a 14-year-old boy with chronic renal failure, whose bad luck did not end there. He became blind following a drug reaction. I asked his parents how he was coping with his blindness. Immediately the boy retorted in an aggressive tone: “Why don’t you speak to me? I’m blind but I’m still a person.” I apologized immediately for my discriminatory behavior.

The broad range of people who are in close relation to patients—elderly persons or children—need to learn to listen with a warm and respectful attitude. Nascher acknowledged a flaw in the analogy between pediatrics and geriatrics. Children’s dependence arouses sympathy, but in the elderly it is met with rejection and lack of sympathy and kindness [4].

Children’s dependence on technology, CPD for instance, arouses tenderness but in the long term, caregivers may exhibit burnout, indolence or lack of responsibility. Thus, sick and dependent young patients, even infants, may be abandoned by their own parents, fathers being the ones who most frequently quit their responsibilities. This situation, in our experience, is unfortunately frequent and a severe problem for the patient and the whole family.

However, the dependent “new” elderly persons who lead an active lifestyle are more widely respected, because they have greater skills to protect their social rights.
Conclusions

Despite the specific characteristics of pediatric and geriatric care, a common approach would help us to achieve major goals for both care-recipients and caregivers, such as a high quality of life and the prevention or reduction of loss of autonomy and independence, financial loss and family disruption.

This paper has emphasized the importance of nonbiological factors such as logistics and adequate communications with patients and contribution of auxiliary staff.

Pediatrics and geriatrics meet in the long-term care of patients within changing settings—hospital, home, outpatient clinics and self-or assisted-care models.

Caregiving for dependent persons, many of them survivors of previously fatal diseases, in extreme ages of life is a complex task. Dialysis and other device-dependent treatments, typical of an increasingly high-tech medicine, impose social and economic costs on both caregivers and care-recipients. Autonomy of patients (especially very young or very old ones) is reduced by their increased dependence on members of their family or others and caregivers’ autonomy is similarly reduced by the need to adjust their schedules and commitments to patients needs. In the long term, this mutual dependence and loss of autonomy may end up having a catastrophic impact on the family in terms of work disruptions or stressed personal relations.

The health team should help families adapt to the new demands on their time and financial resources that RRT and similar long-term treatments entail. Raising awareness of the personal, logistic and financial costs and complexities involved would help families internalize the need to plan adequately for patients needs. In the first moment that exhausts itself quickly, because caregivers underestimated the difficulties involved and leave the patient undercared in the longterm.

The sine qua non of good practice to avoid patients’ preventable loss of autonomy, isolation and subsequent loss of social status can be achieved by showing respect for patients, by promoting their socialization and by providing an effective and pleasant access—to the maximum extent possible—to the health care system. Pediatricians and geriatricians will benefit from interactions, interactive sessions and joint training programs between members of pediatric and geriatric nephrology services aimed at learning from each other’s experiences.

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References