EXECUTIVE SUMMARY

Although informal caregiving or providing unpaid care to others to enable them to become independent or maintain their independence, has been associated with a wide range of negative physical, psychological, social and financial effects, it is expected to increase for at least the next couple of decades in the United States. While online and offline resources for informal caregivers do exist, they are underutilized, and descriptions of how they are helpful when they are used are often limited by focusing on only one type of caregiver, such as a parent caring for an ill child, or by focusing on only one type of care recipient, such as cancer patients. Interviewing 25 informal caregivers who cared for those of different ages and conditions about their authentic experiences using resources to help them, provided a picture of who was using the Internet for caregiving, how it was being used, and if it was helpful in similar or different ways than offline resources. Interviews with this difficult to recruit population were conducted between 2015 and 2017, averaging just over 52 minutes. Comparison of interview transcripts and interviewer memos revealed that one’s position on the informal caregiving team and feelings about that position were related to the resources that they used as well as their caregiving experience overall.

This study produced many novel findings in these regards with future implications as specified below:

(i) Solo caregivers, or those who did not identify other informal caregivers who assisted them with caregiving, were unlikely to acknowledge positive aspects of caregiving and were more likely than other informal caregivers to seek online help. The only caregiving group that was less likely to
identify positive aspects of caregiving were those who provided care to peers, although all peer caregivers who used the internet to assist them found it helpful.

(ii) Whereas informal caregiving-related Internet use was not universal, users indicated that it could be of equivalent or greater helpfulness than offline resources. While the majority who used the internet for caregiving information depicted it as equally or more helpful than offline resources, all of those using the Internet for emotional support described it as equally or more helpful than offline resources.

(iii) Irrespective of a caregiver’s relationship to their care recipient, or their care recipient’s type of condition, informal caregivers reported finding resources helpful in the same ways (e.g., for preparation and/or adaptation to the role), regardless of whether resources were online or offline.

Given that those who persisted in seeking resources were less likely to use the Internet, but Internet users were more likely to identify positive aspects of caregiving, these findings suggest that the Internet offers a good substitute when offline resources and support are lacking or insufficient. As this was a preliminary, exploratory study, it is recommended that future research examine these findings in greater detail and with larger, more diverse samples. The findings also suggest that other members of the informal caregiving team, beyond primary caregivers alone, be included in future policy and practice discussions to provide more accurate and comprehensive understanding of this complex and dynamic phenomenon.